Health Canada Santé Canada

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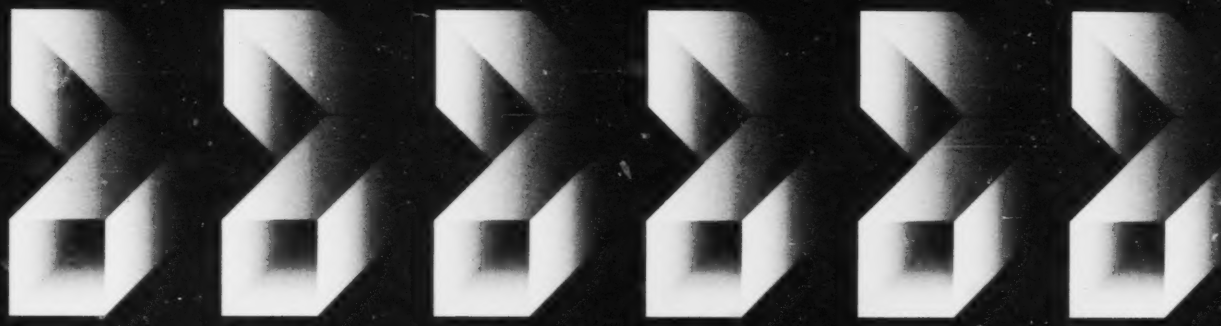

EVALUATION OF THE NATIONAL AIDS STRATEGY - PHASE II

FINAL REPORT

August 1997

Canadä

MISSION STATEMENT

The Evaluation Group helps Health Canada serve Canadians better by providing objective information and advice about the effectiveness of departmental activities and services.

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Le Groupe de l'évaluation aide Santé Canada à mieux servir les Canadiens et les Canadiennes en offrant une information et des conseils objectifs sur l'efficacité des activités et des services du Ministère.

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Evaluation of the National AIDS Strategy
Phase II

Final Report

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This report was originally prepared in English and translated into French. Although the quality of the translation of this document has been reviewed, because of the use of technical/methodol ogical terminology, please note that in the event of any difference of interpretation in the two languages, the English language version should take precedence.

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The final evaluation of the National AIDS Strategy, Phase II was conducted under the general direction of an Evaluation Advisory Committee. The Evaluation Advisory Committee reviewed the consultant's evaluation methodology and workplan, oversaw the execution of the evaluation field work and data analyses, and reviewed the report on the evaluation findings.

The Evaluation Advisory Committee consisted of a senior program manager from each Health Canada Branch participating in the Strategy, as well as from the Correctional Service of Canada and the Medical Research Council of Canada. The Committee included a representative of the Treasury Board Secretariat, Government Review and Quality Services, and was chaired by the Director General, Strategic Planning and Review Directorate, Policy and Consultation Branch.

The evaluation drew heavily upon the cooperation of program managers and regional office staff in federal organizations participating in the Strategy, officials of provincial governments, and stakeholders in non-government organizations, research establishments and community-based organizations. This information was supplemented by the responses of persons living with HIV/AIDS who participated in a survey that was carried out as part of the evaluation, and the input of individuals across Canada who participated in the Non-government Stakeholder Panel Study.

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PREFACE

This document has been prepared by Ekos Research Associates. The analysis and conclusions in this document are those of Ekos Research Associates and do not necessarily reflect the views or policies of Health Canada or the Government of Canada.

Ce document a été préparé par les Associés de recherche Ekos. L'analyse et les conclusions dans ce document sont celles des Associés de recherche Ekos et ne reflètent pas nécessairement les points de vue ou les politiques de Santé Canada ou du Gouvernement du Canada.

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LIST OF ACRONYMS

ACAP	AIDS Community Action Program
ACTSP	AIDS Care, Treatment and Support Program (formerly ACTSU)
ACTSU	AIDS Care, Treatment and Support Unit (now ACTSP)
AEPU	AIDS Education and Prevention Unit (now PCAP)
AIDS	Acquired Immunodeficiency Syndrome
ATIN	AIDS Treatment Information Network
CAHR	Canadian Association of HIV Research
CAN	Cons AIDS Network
CANFAR	Canadian Foundation for HIV/AIDS Research
CAS	Canadian AIDS Society
CATIE	Community AIDS Treatment Information Exchange
CHS	Canadian Hemophilia Society
CIDA	Canadian International Development Agency
CPHA	Canadian Public Health Association
CQCS	Centre québécois de coordination sur le SIDA
CSC	Correctional Service of Canada
CTN	Clinical Trials Network (Canadian HIV Clinical Trials Network)
DAAC	Departmental Aboriginal AIDS Committee
DARC	Departmental AIDS Research Committee
ECAP	Expert Committee on AIDS in Prisons
F/P/T-AIDS	Federal/Provincial/Territorial Advisory Committee on AIDS
HIV	Human Immunodeficiency Virus
HPB	Health Protection Branch
HPPB	Health Promotion and Programs Branch
HPSB	Health Programs and Services Branch (now HPPB)
IDU	Injection Drug User
LCDC	Laboratory Centre for Disease Control
MRC	Medical Research Council
MSB	Medical Services Branch
NAC-AIDS	National Advisory Committee on AIDS
NAS-II	National AIDS Strategy, Phase II
NGO	Non-Governmental Organization

NHRDP	National Health Research and Development Program
PCAP	Prevention and Community Action Program (formerly AEPU)
PLHA	Persons Living with HIV/AIDS
SIU	Simian Immunodeficiency Virus
STD	Sexually Transmitted Disease
TPD	Therapeutic Products Directorate
VLAS	Vancouver Lymphadenopathy Study

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No. 6 Clinical Trials Network Case Study
No. 7 National AIDS Clearinghouse Case Study
No. 8 CATIE — AIDS Treatment Information Network
No. 9 Stakeholder Surveys
No. 10 Survey of People Living with HIV/AIDS
No. 11 Lessons Learned Case Studies
No. 12 Expert Panel Review

RESEARCH REPORTS:

No. 1 Panel Study of Stakeholders
No. 2 Correctional Service of Canada Study

EXECUTIVE SUMMARY

Background

Phase II of the National AIDS Strategy (NAS-II) was implemented by the Canadian federal government from 1993 to 1998. This document reports the culminant point in the evaluation of the Strategy, which began with the preparation of the Evaluation Framework in 1993 and was followed by a Mid-Term Review in 1995. Specifically, this document reports on a final evaluation of NAS-II conducted in the spring of 1997.

NAS-II received a total of $212 million over 1993 to 1998. Using a partnership approach, its activities were focussed in four main areas: education and prevention, research and epidemiological monitoring, community development and support for non-governmental organizations, and care, treatment and support. The Strategy had four objectives: 1) stop the spread of HIV, 2) search for effective vaccines, drugs and therapies, 3) treat, care and support people infected with HIV, their caregivers, family and friends, and 4) implement NAS-II activities effectively.

As required by the Treasury Board Policy on Review and Evaluation, the evaluation focused on three main issues: 1) the relevance and continued need for federal HIV/AIDS programs and activities; 2) the accomplishments of the Strategy and its success in meeting its goals; and 3) the cost-effectiveness of the Strategy and possible alternatives for the federal role. The evaluation methodology sought to ensure input from all sectors of the HIV/AIDS community in Canada and all stakeholders in NAS-II. It included the following components:

- an internal review of coordination and effectiveness within Health Canada;
- a provincial survey and inventory in provincial/territorial governments and their partner organizations;

- ❑ surveys of representatives of local and regional HIV/AIDS NGOs and community-based groups, professional associations, HIV/AIDS researchers, ethnocultural organizations, Aboriginal organizations, and private sector organizations;
- ❑ a survey of people living with HIV/AIDS;
- ❑ case studies of the National AIDS Clearinghouse, the AIDS Treatment Information Network, and the Clinical Trials Network;
- ❑ Lessons Learned Case Studies illustrating areas of significant NAS-II intervention or concern;
- ❑ international comparative case studies of government AIDS programs in three comparable countries;
- ❑ a two-wave panel study of non-government stakeholders assessing responsiveness of NAS-II over time;
- ❑ a review of the epidemiology of HIV/AIDS in Canada; and
- ❑ a parallel study conducted by Correctional Service of Canada examining issues related to HIV/AIDS in federal prisons.

Finally, a panel composed of nine Canadian and international experts in various aspects of HIV/AIDS reviewed the evaluation findings and commented on the validity of the conclusions given the evidence presented.

Main Findings

Continued Relevance

- ❑ There is a wide consensus across all those consulted that the elements currently included in the National AIDS Strategy are both comprehensive and appropriate. However, some dissatisfaction with balance among elements of the Strategy, that is, among research, care and prevention, was found, with support for greater investment in research and prevention.

- ❑ Overall, NAS-II has succeeded in harmonizing its activities with those of the various other jurisdictions involved in HIV/AIDS. Education and prevention activities were identified by both federal and provincial representatives as areas for greater sharing or joint responsibility. The appropriateness of federal support to community-based organizations was questioned, but without consensus.

- ❑ While there is no significant duplication between federal and provincial/municipal activities, neither is there a great deal of jointly-shared, synergistic collective effort. The National AIDS Strategy can still best be described as a federal, rather than truly national, AIDS Strategy.

- ❑ Deficiencies in NAS-II noted in the Mid-term Review in terms of coordination and monitoring still show room for improvement. Interdepartmental, international and federal/provincial coordination were also identified as areas of concern in this evaluation.

- ❑ The evaluation findings show that NAS-II has helped the federal government's partners, particularly community-based groups, become more capable in developing, implementing and delivering programs and services.
- ❑ Although progress is being made toward the development and implementation of a multi-disciplinary program framework to address HIV/AIDS issues in Canadian prisons, considerable further work remains to be completed.
- ❑ About three quarters of respondents to the survey of people living with HIV/AIDS feel that at least some effort is being made in Canada to help those living with HIV/AIDS.
- ❑ There was an overwhelming consensus among all NAS-II partners on the continued need for a national AIDS Strategy as well as federal involvement in HIV/AIDS programming, in a leadership as well as funding role.

Accomplishments and Success in Achieving Objectives

- ❑ Overall, the National AIDS Strategy-Phase II has been moderately successful in achieving its objectives.
- ❑ The qualitative, survey, and epidemiological data converge to the conclusion that the National AIDS Strategy has not succeeded in *stopping the spread of HIV*, although gains have been made in terms of education and awareness. Increases in the rate of new HIV infections among some subgroups during the period covered by NAS-II support the conclusion that the burden of HIV illness on Canadians cannot be said to be declining.
- ❑ Greatest success in reaching target groups has been among men who have sex with men. Regarding the emergence of new epidemics among injection drug users and Aboriginal people, NAS-II has been less effective. Although considerable effort has already been made, major challenges remain to deal with the epidemic in these groups.
- ❑ NAS-II has been successful in *ensuring the provision of care, treatment and support to people living with HIV/AIDS*, through the creation and mobilization of an infrastructure of non-governmental organizations and through development of professional skills. Recent declines in overall deaths from AIDS are attributed largely to improved treatments, made available in part through NAS-II. A large proportion of respondents to the survey of people living with HIV/AIDS state they are receiving information, treatment and moral support.

- In terms of *searching for effective vaccines, drugs and therapies*, mortality and morbidity rates among HIV/AIDS patients have decreased considerably (20 to 30 per cent decrease in mortality) during the life of the Strategy, in part because of new treatment regimens developed through research supported by NAS-II.

- Several sources of evaluation data converge to suggest that NAS-II research activities have effectively contributed to NAS-II objectives, especially of ensuring effective treatment for people living with HIV/AIDS.

- The Strategy has been successful in expanding the knowledge base through comprehensive and reliable AIDS surveillance and epidemiological data, although work remains to be done in the area of HIV surveillance systems, particularly in high-risk groups.

- Three mega-projects led by non-governmental associations — the Canadian HIV Clinical Trials Network, the Canadian Public Health Association National AIDS Clearinghouse and the AIDS Treatment Information Network, have all made contributions to the achievement of NAS-II objectives.

Cost-effectiveness and alternatives

- The available evaluation data suggest that NAS-II has been reasonably cost-effective. Contributing to cost-effectiveness are partnerships with volunteer-based organizations, leveraging of costs, and development of transferable models.

- Alternative sources of support to NAS-II components were difficult to identify, but included greater contributions from the private sector, greater insistence on funding responsibility from provinces currently not making significant contributions and greater contributions from provinces in cost-sharing. Although community-based organizations and the national mega-projects have been asked to develop alternative sources of funding, progress toward this has been slow.

Overall Conclusion

The evaluation findings show, overall, that the National AIDS Strategy continues to be relevant and that there is strong support for a continued federal role. The Strategy has been moderately successful in achieving its objectives. Success has been especially evident in care, treatment and support and research. However, evolution in the epidemic indicates that there are new challenges to be faced in terms of prevention in marginalized groups, notably Aboriginal people and injection drug users. Finally, insofar as the data available allow us to draw conclusions, the National AIDS Strategy has been relatively cost-effective.

CHAPTER

1

INTRODUCTION

Phase II of the National AIDS Strategy (NAS-II) was implemented by the Canadian federal government from 1993 to 1998. This document represents the culminant point in the evaluation of the Strategy, which began with the preparation of an Evaluation Framework in 1993 (Health Canada, 1994a) and a Mid-Term Review in 1995 (Health Canada, 1996). Specifically, this document reports on a final evaluation of NAS-II, conducted in the spring of 1997. The evaluation was managed by the Strategic Planning and Review Directorate of the Policy and Consultation Branch of Health Canada, in consultation with an Evaluation Advisory Committee composed of representatives of all Health Canada branches involved in the Strategy as well as of the Medical Research Council, Treasury Board and Correctional Services Canada.

1.1 Evaluation, Issues and Questions

As required by the Treasury Board Policy on Review and Education, the evaluation of NAS-II examined three main issues and ten evaluation questions:

Issue 1:

- ❑ **The relevance of the National AIDS Strategy, and whether there is a continued need for federal HIV/AIDS programs and activities.**

Evaluation questions

1. How comprehensive and appropriate are the elements of NAS-II?
2. How complementary are the elements of NAS-II? (Is there duplication or overlap among the activities and components, or with activities of other jurisdictions?)
3. How appropriate are the mechanisms in place for coordination and collaboration (departmental, federal, national (provinces, territories and NGOs) and international)?
4. To what extent have the capabilities of the federal government's partners to develop, implement and deliver services and programs been enhanced?

Issue 2:

☐ **The accomplishments of NAS-II and the success of the Strategy and its components in achieving the Strategy's goals.**

Evaluation Questions

5. How effective were the research and development activities of NAS-II?
6. How effective has NAS-II been? (i.e., what added value has it generated?)
7. What successes has NAS-II had in responding to the HIV/AIDS epidemic(s)?
8. How effectively has the National AIDS Secretariat/Division monitored the implementation of NAS-II?
9. How effectively has the National AIDS Secretariat/Division facilitated the management of strategic issues?

Issue 3:

☐ **The cost-effectiveness of NAS-II and possible alternatives for the federal role.**

Evaluation Question

10. How cost-effective was NAS-II?

Specific evaluation questions examined followed closely those outlined in the Evaluation Framework prepared by Health Canada in 1993, with some changes in focus as requested by the Evaluation Advisory Committee.

1.2 Evaluation Context

Three factors are important to understanding the context in which the evaluation of NAS-II has occurred.

First, as Phase II of the National AIDS Strategy comes to the end of its funding in March 1998, the Canadian response to AIDS has become highly complex, given the sheer numbers of stakeholders involved at all levels of government and outside government. For the evaluation to be credible, balanced and meaningful, it was important to ensure that input was obtained from all sectors of the AIDS community.

Moreover, Phase II of the National AIDS Strategy was implemented during a period of upheaval in most provincial health systems and within Health Canada. Most Canadian provinces have now undergone significant health reform, with strong emphasis on rationalization and regionalization of services. At the same time, Health Canada has been reorienting its programs towards a population health and health systems approach, focusing on macro-level and intersectoral determinants and less on local or community processes. This has been accompanied by the sunsetting of several major programs and research initiatives. These changes are linked to an overall evolution in the federal role and in sharing of responsibilities between the federal and provincial governments.

Finally, the evaluation was begun in a climate of apprehension and anxiety about the future of the Strategy, as no announcement of continued support had yet been made. However, in the federal election campaign of May and June, the party currently in power and now re-elected promised to provide some form of continued support. The Minister of Health was also conducting consultations with AIDS organizations concurrently with the evaluation as to the future of the AIDS Strategy.

The Mid-Term Review of NAS-II (Health Canada, 1996) focused on four main issues: coordination, both within Health Canada and among partners;

implementation of the Strategy; balance among the program components; and information adequacy for monitoring and evaluation. Although the overall conclusion of the Mid-Term Review was that the implementation of NAS-II was satisfactory, a number of issues and concerns with other aspects of the Strategy were identified. These were again addressed in the final evaluation reported here.

1.3 Program Description

Phase I of the National AIDS Strategy reflected the social and medical realities of AIDS as they had been experienced throughout the 1980's. It emphasized both partnership among governments and other organizations, and balance between prevention, search for effective treatments, and care. During 1990 to 1993, the Strategy supported work by the federal government in education and prevention; research; care, treatment and support; support to national non-governmental organizations as national partners; support to community-based groups working in education, prevention, care and treatment, support and advocacy; and coordination and collaboration, including creation of the National Advisory Committee on AIDS (NAC-AIDS) and the Federal/Provincial/Territorial Advisory Committee on AIDS (FTP-AIDS).

In 1992, the federal government once again conducted broad consultations to validate the framework for action of Phase I of the Strategy. These consultations suggested that this framework was valid, and were followed in March 1993 by the announcement of Phase II.

(a) Objectives and Policy Themes

Following Phase I of the National AIDS Strategy (1990-1993), Phase-II reaffirmed the federal commitment to address HIV and AIDS in Canada in a concerted, collaborative fashion. The three objectives of NAS-II are:

- ☐ stop the transmission of HIV;
- ☐ search for effective vaccines, drugs and therapies; and
- ☐ treat, care for and support people infected with HIV, their caregivers, families and friends.

A fourth, overarching goal is to:

- ☐ implement NAS Phase II activities effectively.

While the objectives of the Strategy were reaffirmed, the Phase II program was adapted in recognition of significant evolution of the epidemic and its parameters in Canada. It was increasingly recognized that infection was proceeding at different rates in different groups, suggesting a need for specific strategies aimed at specific target groups, notably in Aboriginal people, injection drug users, women, street-involved youth and ethno-cultural groups. It was further recognized that although public awareness had increased greatly, there was still a need to go beyond providing information to strengthen skills among high-risk groups. Moreover, advances in testing, diagnosis and treatment were contributing to longer survival after infection with the virus. This created a need to manage care, treatment and support in models more similar to chronic than acute disease, and reinforced the need to combat isolation, financial insecurity, marginalization and service fragmentation for those living with the disease.

These adaptations were reflected in the five policy themes of NAS-II:

- *enhancing partnerships:* building from partnerships with government, non-government, and private organizations developed in Phase I, this was to be a major focus of Phase II;
- *recognizing HIV as a chronic and progressive condition:* providing care, treatment and support services for people living with HIV throughout their disease;
- *promoting health for people living with HIV/AIDS:* enabling people living with HIV/AIDS to develop and maintain control over their health;
- *encouraging supportive social environments:* making institutions effective, more inclusive, humane, tolerant, compassionate and supportive; and
- *promoting and sustaining healthy behaviour:* prevention and education focused on acquisition of preventive behavioral skills and support.

(b) Activities and Funding

Funding for NAS-II, a total of $203.5 million over 1993 to 1998, was allocated to Health Canada by Cabinet. An additional $7.5 million was allocated over the same period for urgent issues from within Health Canada's budget. Health Canada allocated a portion of NAS-II funds, $400,000 annually reduced to $300,000 in 1996/97, to the Solicitor General to fund AIDS activities undertaken by Correctional Service Canada with inmates and staff of Canadian prisons. In addition, the Medical Research Council allocated at least $2 million per year for clinical and biomedical research related to HIV/AIDS.

Health Canada funding for NAS-II was allocated among the five components of the framework for action, that is, among five generic types of activities[1]:

- *coordination and collaboration:* $7.5 million, or $1.5 million per year, to provide federal leadership and national coordination, to facilitate coordination and HIV/AIDS infrastructure, and greater Canadian contribution to international efforts;

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[1] These figures present the allocations although there may be slight year-to-year variations.

- ☐ *education and prevention:* $31 million, or $6.2 million per year to be aimed at innovative prevention and education strategies for high risk groups including men who have sex with men, injection drug users (IDUs), Aboriginal people, women at risk, marginalized youth, prison populations and sex workers;
- ☐ *research and epidemiological monitoring:* $89.2 million, or $17.84 million per year, for research on vaccines and treatments and on epidemiological monitoring, and to develop an national research planning process;
- ☐ *community development and support for non-governmental organizations (NGOs):* $49 million, or $9.8 million per year, to support community and national NGOs in community development and in providing prevention and care and support programs; and
- ☐ *care, treatment and support:* $26.8 million, or $5.36 million per year to support and promote the health of people living with HIV/AIDS as a chronic disease and to provide information on treatments and care and support systems.

Table 1.1, below, illustrates a more detailed breakdown of funding among NAS-II components.

TABLE 1.1
Allocation of Funds Across NAS-II Components within Health Canada, 1995-96

Initiative	Total ($M)
Community Development and Support to National NGO's	
Health Promotion and Programs Branch	
• AIDS Community Action Program	7.8
• Support to National NGO's	2.0
Education and Prevention	
Health Promotion and Programs Branch	
• Development of Education/Prevention	2.4
• CPHA National AIDS Clearinghouse	0.8
• Inter/intradepartmental Coordination	0.6
Medical Services Branch (Aboriginal AIDS Programs)	
• Development of Community-based Education and Training Programs	1.83
• Professional and Non-professional Education and Training Programs	0.43
• Program Development/Sero Prevalence Study	0.24
Research and Epidemiological Monitoring	
• National Health Research and Development Program	5.7
• Canadian HIV Clinical Trials Network	3.0
• Care, Treatment and Support Research (psychosocial/quality of life support and research)	1.0
Health Protection Branch	
• Safety of the Canadian Blood Supply	0.8
• Epidemiology and Surveillance	3.12
• Laboratories and Research	3.63
• Internal/External Relations	0.45
Health Promotion and Programs Branch	
• Social Support Initiative	0.6
Care, Treatment and Support	
Health Promotion and Programs Branch	
• AIDS Treatment Information Network	2.0
• Support to Professional and Non-professional Education and Training	1.7
• Model Program Demonstration and Evaluations	0.7
• Social Support Initiative	0.4
Coordination and Collaboration	
• Overall management of NAS (including NAC-AIDS, F/P/T-AIDS, National Research Forum, National Partners Forum)	1.5

(c) Components

The National AIDS Strategy consists of 12 responsibility centres and several additional components, each of which is expected to make a unique and effective contribution to the overall goals of the Strategy. Although their names have changed in the course of departmental reorganization during the use of the Strategy, we refer to them in this report by their original names (with the new names provided in parentheses below). The components of NAS-II are:

Health Canada Components

- The **National AIDS Secretariat**, now replaced by the **HIV/AIDS Policy and Coordination Unit of the Health Promotion and Programs Branch:** the focal point for all federal activity in HIV/AIDS and responsible for developing overall financial accountability systems; monitoring and providing strategic advice on implementation of NAS-II as a whole; facilitating the assessment and evaluation of the Strategy and its initiatives; encouraging private sector participation; facilitating a national AIDS research planning process; and ensuring effective and coordinated federal communication. Its coordination role extends to all divisions of Health Canada involved in the Strategy, as well as to the other federal ministries involved, the National Advisory Committee on AIDS and federal/provincial/territorial, national and international organizations;
- **Health Protection Branch, Laboratory Centre for Disease Control (LCDC), Division of HIV/AIDS Surveillance and Division of HIV Epidemiology**: responsible for AIDS surveillance and reporting;
- **Health Protection Branch, Laboratory Centre for Disease Control (LCDC), Division of HIV/AIDS Laboratories and Research**: responsible for laboratory reference and quality control services;
- **Health Protection Branch, Drugs Directorate (now Therapeutic Products Directorate (TPD)), Bureau of Biologics (now Bureau of Biologics and Radio-Pharmaceuticals)**: responsible for regulating biologically-based drugs and regulating use of test kits for blood safety;

- **Health Protection Branch (HPB), Drugs Directorate (now TPD), Bureau of Human Prescription Drugs (now Bureau of Pharmaceutical Assessment)**: responsible for regulating HIV/AIDS drugs, reviewing applications for clinical trials in Canada and for facilitating access to experimental therapies through the Special Access Program;

- **Health Protection Branch, Drugs Directorate (now TPD), Bureau of Drug Research**: responsible for providing regulatory research support and scientific expertise to the Drugs Directorate and for coordinating the Expert Committee on HIV Therapies and the Expert Advisory Committee on Blood Regulation;

- **Health Programs and Services Branch (HPSB) (now Health Promotion and Programs Branch (HPPB)), Health Promotion Directorate, AIDS Community Action Program (ACAP)**: funding to community-based not-for-profit organizations including off-reserve Aboriginal groups to develop education, prevention, care and support programs;

- **Health Programs and Services Branch (now HPPB), Health Promotion Directorate, AIDS Education and Prevention Unit (AEPU) (now Prevention and Community Action Program (PCAP))**: supporting national education and prevention strategies aimed at vulnerable groups, and funding the national NGO partners, the Canadian AIDS Society, the Canadian Hemophilia Society, the Canadian Public Health Association **National AIDS Clearinghouse**, and the Correctional Service of Canada AIDS Program;

- **Health Programs and Services Branch (now HPPB), Health Services Directorate, AIDS Care, Treatment and Support Unit (ACTSU) (now AIDS Care Treatment and Support Program, or ACTSP)**: responsible for supporting professional and non-professional education and training, psychosocial/quality of life support and research initiatives, model program development, demonstrations and evaluation, and the HIV/AIDS treatment information services: the **AIDS Treatment Information Network (now known as CATIE's Network)** and the **HIV Clinical Trials Network**;

- **Health Programs and Services Branch (now HPPB), Extramural Research Division (now Research and Knowledge Development Division), National Health Research and Development Program (NHRDP)**: funding for investigator-initiated competitive HIV/AIDS research in areas not covered by the Medical Research Council. Clinical/biomedical research and personnel support in the area of AIDS was through a collaborative initiative with the Medical Research Council, administered by NHRDP; and

- **Medical Services Branch — First Nations and Inuit Health Services**: responsible for providing community-based AIDS programs and services for on-reserve registered Indians and the Inuit.

Other Federal Components

- **Medical Research Council (MRC)**: funding for investigator-initiated research related to HIV and AIDS;[2]
- **Correctional Service of Canada**: responsible for developing a comprehensive approach to HIV/AIDS policies in federal prisons;
- **Citizenship and Immigration and Revenue Canada — Customs and Excise, Immigration Operations**: training immigration, customs and visa officers;
- **Justice Canada**: overseeing of human rights issues related to HIV/AIDS;
- **Canadian International Development Agency**: supporting HIV/AIDS related activities as part of its international development mandate; and
- **International Development Research Centre**: contributing to strengthened research capacity on HIV/AIDS in developing countries.

Non-Governmental Organization Mega-Projects

- **The Canadian Public Health Association National AIDS Clearinghouse:** delivered under a contribution agreement, established to collect and distribute HIV/AIDS materials dealing with prevention and education;
- **The AIDS Treatment and Information Network (ATIN):** a national AIDS Treatment Registry; and
- **The Canadian HIV Trials Network:** providing infrastructure support for Canadian clinical trials of HIV therapeutic agents and operating as a coordination, information and data exchange mechanism.

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[2] All new applications received during NAS-II up to November 1995 were reviewed and funded through the NHRDP/MRC Collaborative Initiative on AIDS Research. After that time, AIDS applications were reviewed through MRC's regular programs.

Government Advisory Mechanisms

- **National Advisory Committee on AIDS (NAC-AIDS):** serving as an advisor to the Minister of Health.
- **Federal/Provincial/Territorial Advisory Committee on AIDS:** providing policy advice to the Conference of Deputy Ministers of Health.

(d) Stakeholders

Other than the above units and organizations, NAS-II has a number of partners and stakeholders. Those consulted during the evaluation were:

- provincial and territorial governments;
- umbrella nongovernmental organizations or provincial coalitions;
- community-based groups;
- professional associations and licensing bodies;
- HIV/AIDS researchers;
- private sector firms;
- community-based Aboriginal groups;
- community-based ethnocultural groups; and
- people living with HIV/AIDS.

(e) Evaluation Methodology

The evaluation methodology included seven sources of information. In order to permit triangulation of findings across data sources, each information source addressed several of the evaluation questions. The sources were:

- Internal Review of coordination and effectiveness within Health Canada, conducted through key informant interviews with headquarters and regional Health Canada staff in all program components and analysis of plans, progress reports and other documents (32 respondents);

- Provincial Survey and Inventory; detailing current provincial activity in HIV/AIDS and assessing complementarity with federal activity, as well as determining views of provinces and territories on future roles; conducted through key informant interviews with representatives of each provincial/territorial government and with key umbrella non-government organizations in each province/territory, with review of plans, progress reports and other documents (24 respondents); Summaries may be found in Technical Report No. 4;

- Stakeholder Surveys consisting of telephone interviews with representatives of samples of organizations in six key stakeholder groups: local and regional HIV/AIDS NGOs and community-based groups, professional associations, HIV/AIDS researchers, ethnocultural organizations, and Aboriginal organizations (201 respondents). Detailed results are presented in Technical Report No. 9;

- Survey of People Living with HIV/AIDS, using an anonymous, self-administered questionnaire distributed through community-based groups responding to the Stakeholder Surveys and through a random sample of physicians treating HIV/AIDS patients (230 respondents). Detailed results are presented in Technical Report No. 10;

- Case studies of the National AIDS Clearinghouse, ATIN and the Clinical Trials Network; conducted using key informant interviews with individuals both within and outside these components, review of relevant documentation, and surveys of awareness and satisfaction with their services. Detailed results are presented in Technical Reports Nos. 6, 7 and 8;

- Lessons Learned Case Studies illustrating areas of significant NAS-II intervention or concern. Seven case studies were conducted using key informant interviews and review of relevant documentation. Detailed results are presented in Technical Report No. 11. Summaries are presented throughout this report in sections where they can qualitatively illustrate other findings;

- International Comparative Case Studies of government AIDS programs in three comparable countries. Detailed results are presented in Technical Report No. 5;

- A two-wave panel study of non-government stakeholders (conducted by Brighton Research), designed to assess the responsiveness of the Strategy over time to issues of information availability, coordination and effectiveness (112 respondents at two time points, in 1995 and 1997). Detailed results are presented in Research Report No. 1;

- A background paper on the epidemiology of HIV/AIDS in Canada, available as Technical Report No. 3; and

- A parallel study conducted by Correctional Service of Canada examining issues related to HIV/AIDS in federal prisons, conducted using key informant interviews, review of existing data, and document analysis (Research Report No. 2).

Finally, an Expert Panel composed of nine Canadian and international experts was asked to review the evaluation findings and comment on the validity of the conclusions given the evidence presented. Detailed results are presented in Technical Report No. 12.

The specific data collection and analysis procedures are described in Technical Report No. 2, which also presents the evaluation instruments.

In the following chapters, the evaluation findings from these components have been synthesized and integrated in order to provide a balanced and complete assessment of the Strategy in line with the evaluation issues and questions. Note that the coverage provided to the elements of NAS-II should not be interpreted as a reflection of their relative importance. Rather, more coverage is given to issues or elements which are more controversial or which generated more divergent inputs. In the interest of brevity, the information presented in this report has been condensed and is limited to that which is needed to support and illustrate the main findings.

CHAPTER

2 EPIDEMIOLOGY OF HIV/AIDS IN CANADA

2.1 Introduction

This chapter is a summary of a non-technical, background paper to the evaluation of the National AIDS Strategy, Phase II (NAS-II — Technical Report No. 3). Its objective is to describe the evolution of HIV/AIDS in Canada since the beginning of the epidemic, but with particular attention to the time period and the population groups where NAS-II effects could have been felt. Because the epidemiological methods used to collect, analyze, correct and interpret HIV and AIDS information are so new, there is naturally controversy in the epidemiological community about which are acceptably rigorous. This report relied on published information which has passed rigorous review processes inside its sponsoring organizations and in external peer review. For many of these data, we are especially indebted to the Laboratory Centre of Disease Control of Health Canada.

If the National AIDS Strategy has been successful in building or supporting an infrastructure that can slow the epidemic, its effects should be visible, over and above naturally-occurring changes or changes effected by other agencies, in terms of reduced transmission of HIV and better, longer lives for those living with AIDS-related illness. This means that we must look specifically at how much transmission appears to have been prevented in NAS-II target group members not already infected before 1993 (NAS-II prevention objective) and how much HIV and AIDS treatments have improved outcomes for people already infected before 1993 and who have become infected since (NAS-II treatment objective). This paper brings together information from several sources to look at how the epidemic has evolved and how its course may have been altered during the period covered by NAS-II, and perhaps due in part to the actions of NAS-II and its partners.

However, a number of factors limit our ability to discern whether or not NAS-II has had any effect on HIV/AIDS in Canada. These include problems of measurement and classification[3] (changing definitions of clinical AIDS cases; under-reporting of AIDS cases; unreliability in reports of AIDS-related deaths and misdiagnoses; lack of a national standard for HIV reportability; duplicate test results in HIV infection data; overlap between HIV and AIDS databases; barriers to testing; exposure categories that are not mutually exclusive and so require assignment of cases to one category or another); the changing nature of the epidemic over the period of NAS-II (waves of infection in different subpopulations; increased delay of AIDS onset due to better therapies; increased survival for people with AIDS; differential susceptibility and resistance in some populations); and uncertainties about what effects could be attributed to NAS-II (due to unassessed effects of other interventions; differential effectiveness of NAS-II components). Taken together, these factors suggest that we must exercise caution in trying to identify precisely the impact of the National AIDS Strategy on the evolution of the epidemic in Canada. At most, we will be able to show that there is an association between the introduction of NAS-II and changes in the epidemic, but that those changes may also be, to an unknown extent, influenced by other factors.

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[3] It is important to note that these problems are common throughout all epidemiological surveillance systems worldwide.

2.2 Overall Situation

Acquired Immunodeficiency Syndrome (AIDS) and the virus which causes it, Human Immunodeficiency Virus (HIV) have been present in Canada since 1978. As of April 15, 1997, 14,836 cases of AIDS and 10,837 deaths have been reported[4]. As of the end of 1996, an estimated 50,000 to 54,000 Canadians had been infected with HIV and between 36,000 and 42,000 were living with HIV or AIDS[5]. Cumulative AIDS incidence rates across the industrialized world show Canada to be a country with a moderate level of infection, lower than that in the United States, France, Italy and Spain, but higher than most other comparable European countries.

2.3 HIV in Canada in Relation to NAS-II

From 1985 to 1994, 33,520 positive HIV tests were recorded in Canada. In 1995, another 3,093 cases were identified. About 3,000 to 5,000 new infections occurred in 1996, up from the estimated 2,500 to 3,000 per year in 1989 to 1994[6]. Note that the wider range in the 1996 estimate represents increased difficulty in making these estimates due to changes in the natural history of the epidemic: the methods used to estimate HIV infection must now be adapted to new populations and to account for effects of new treatments.

For half of the positive HIV tests from 1985 to 1994, no known risk factor was available. Men who have sex with men (excluding those who are also injection drug users) accounted for 37 per cent of positive tests, or almost three-quarters of positive tests among those with at least one known risk factor. In contrast, in 1995, this category accounted for 27 per cent of positive tests or 47 per cent of positive tests among those with at least one known risk factor. The two injection drug use categories (including injection drug users who are also men who have sex with men) were associated with 5.3 per cent of all positive tests where at least one risk factor was known. Finally, 10 per cent of positive tests between 1985 and 1994 were taken by women, whereas in 1995, 19 per cent of positive tests were taken by women.

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[4] Health Canada, Laboratory Centre for Disease Control (LCDC), Quarterly Surveillance Update, May, 1997.

[5] Health Canada, LCDC, Epi Update, May, 1997.

[6] Health Canada, LCDC, Epi Update, May, 1997.

An inventory of a total of 88 studies of HIV incidence and prevalence in specific samples is regularly compiled by LCDC[7]. These include studies where data is collected in sentinel hospitals, sexually transmitted disease (STD) clinics, physicians' offices, outreach clinics, needle exchanges, prisons and blood donor clinics. These studies suggest that new infections are becoming less common among men who have sex with men, especially the older members of this group[8]. The most recent data suggest that at the same time, incidence appears to be increasing among injection drug users, especially in Vancouver[9].

Overall, data on HIV infection in Canada suggest that rates and patterns of HIV transmission in Canada are changing, probably in response to a number of factors. Although rates of infection among the older cohorts of men who have sex with men may be stabilizing or declining, they may be increasing among younger cohorts in this group, among Aboriginal people, among injection drug users and among women[10]. It is currently believed that the rate of HIV transmission has increased from about 1991 on. About half of the 3,000 to 5,000 new infections per year are believed to occur in injection drug users. About 35 per cent are occurring in men who have sex with men, with the

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7. Health Canada, LCDC, Inventory of HIV Incidence and Prevalence Studies In Canada, May 1997.

8. For example, Vancouver Lymphadenopathy AIDS Study, cited in Health Canada, Inventory of HIV Incidence and Prevalence Studies In Canada, 1997.

9. Patrick, D., Strathdee, S., Currie, S., et al. (1997) HIV Incidence in the Vancouver IDU Study Cohort. Abstract no. 219, Canadian Association of HIV Research Conference, Ottawa.

10. Health Canada, LCDC, Epi Update, May 1997.

remaining 15 per cent occurring through heterosexual transmission, some of which may be related to IDU activity.

2.4 AIDS in Canada in Relation to NAS-II

Up to the end of 1996 and after adjustment for reporting delay, the estimated total number of AIDS cases in Canada was 17,836. Far more men than women have been diagnosed with AIDS, reflecting the transmission pattern among men who have sex with men. The cumulative number of cases has risen steadily and sometimes sharply since 1985, but has recently begun to slow down[11]. Given the average ten-year lag between HIV infection and emergence of AIDS, most of these cases were likely infected with HIV at some time before the introduction of the National AIDS Strategy Phase I or Phase II. Transmission through the blood supply, which accounts for a total of 587 reported adult AIDS cases[12], was reduced to virtually zero by the end of 1985.

Because the total number of individuals in each exposure category (e.g., total number of injection drug users in Canada in a given year) is not known, it is difficult to calculate precisely the rate of infection in each identified risk group. However, we can still examine changes in the overall composition of the epidemic over time by looking at the percentage of cases in each exposure category. (Note, however, that this comparison of proportions does not take into account decline in the overall number of cases.) The proportion of cases who were men who have sex with men (excluding men who have sex with men and who are also injection drug users) declined from a high of 80.1 per cent of cases in 1987, to 69.2 per cent in 1995. The proportion of cases among injection drug users has increased over this period, from 3.2 per cent in 1985 to 14.2 per cent in 1995. The proportion of all AIDS cases among those having heterosexual contact with a person at risk has also risen steadily over the past five years, from 9.8 per cent of cases in 1991 to 16.6 per cent of cases in 1995. The number of cases among women and children has also continued to increase. Cases among Aboriginal people have risen quite sharply. The proportion of total AIDS cases who are Aboriginal people was 1.4 per cent in 1984/89 and 3.6 per cent in 1993/95[13].

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[11] Health Canada, Laboratory Centre for Disease Control (LCDC), Quarterly Surveillance Update, May, 1997.

[12] Note that the number of transmissions of HIV through the blood supply, believed to be about 1,200 in total, greatly exceeds the reported AIDS cases with receipt of blood products as a risk factor. This is because many people infected through the blood supply were never registered as AIDS cases.

A total of 10,837 deaths have been reported among AIDS cases. Throughout the early 1990's death followed the diagnosis of AIDS in one to five years. The pattern of AIDS deaths over the period 1985 to 1995 therefore closely follows the pattern of diagnoses several years previously. A 20 per cent to 30 per cent decline in deaths attributed AIDS has recently been reported[14]. This decline is believed to largely reflect better care and treatment, for example reduced death rates for individuals on antiretroviral treatment, to which the Strategy has contributed[15].

2.5 Conclusion

The true effects of the National AIDS Strategy on the evolution of HIV/AIDS in Canada may not be clearly visible until five to 10 years from now. During the period that NAS-II has been in place, epidemiological progress seems to have occurred in two areas: lower rates of transmission of HIV among men who have sex with men, and in fewer deaths due to AIDS. During the same period, infection rates have increased among youth, injection drug users, Aboriginal people and women. The increase in transmissions among injection drug users may also be a function of the greater risk of transmission per episode associated with needle sharing than with sexual activity. It is likely to be exacerbated in populations which inject drugs more frequently, such as users of injectable cocaine which is currently prevalent in Canada. Because the number of new HIV infections has increased since the early 1990's and because survival after infection has increased due to therapy, the burden of HIV illness on Canadians cannot be said to be declining.

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[13] Health Canada, LCDC, Epi Update, December 1996.

[14] Health Canada, Laboratory Centre for Disease Control (LCDC), Quarterly Surveillance Update, May, 1997.

[15] Canadian HIV Trials Network: Background Information, January 28,1997; and British Columbia Centre for Excellence in HIV/AIDS, The Battle Isn't Over. Forecast: The Journal of the BC Centre for Excellence, March 1997.

CHAPTER

3 CONTINUED RELEVANCE OF THE NATIONAL AIDS STRATEGY

In this chapter, evaluation data pertaining to the continued relevance of the National AIDS Strategy are presented, integrated across several data sources.

3.1 Comprehensiveness, Appropriateness, and Balance of Federal Activities

The comprehensiveness and appropriateness of current federal activities was discussed with Health Canada staff in all regions, NAC-AIDS and F/T/P Committee members, provincial and territorial government representatives and provincial/territorial AIDS organization representatives. Overall, respondents agreed that federal activities are comprehensive and appropriate. Respondents agreed strongly that Health Canada has played an important role in addressing the epidemic, and that the federal government continues to have an important role to play.

In general, key informants believed that the level of effort or resources was sufficient to have had an important effect on the HIV/AIDS epidemic in Canada, though many believe the level of funding could have been greater to fully address the various and emerging aspects of the disease. It was noted, for example, that the $40 million annual allocation to HIV/AIDS was well below the level of funding originally recommended. Suggestions to improve the comprehensiveness of the Strategy included:

- improving the reporting of ethnicity in HIV/AIDS cases and addressing multicultural issues and barriers;
- improving activities in the Correctional Service of Canada; and
- strengthening relationships with the provinces/territories and non-governmental organizations.

Overall, participants in the key informant components of the evaluation generally approved of the current balance among the program components (i.e., research, education/prevention, treatment, care and support). It was noted by some, however, that future activities would need to include a shift toward more resources for care and treatment if infection rates continue to increase and as current HIV cases evolve into full blown AIDS, particularly among the Aboriginal population. Respondents were also concerned about the development of resistances to antiretroviral drugs.

Other respondents believed that funding for research could be increased. Research support is considered to be a highly appropriate role for the federal government to play, though funding in this area must be accompanied by a strong peer review process. It was noted that Canada's level of funding for research activities is proportionately smaller compared to the United States. Using the US investments as a guideline, the effort in Canada should have been about $70 million annually adjusting for the size of the HIV/AIDS epidemic in Canada. It was suggested by a minority of respondents that given the size of the research community in Canada, this level of funding could not, in fact, be absorbed without further support to training and career development in HIV/AIDS research. Nevertheless, there is a perceived need to increase research funding beyond current levels. Note, however, that international comparisons showed that Canada's commitment to research as a *proportion* of program funds is relatively greater than that in other countries.

Representatives of stakeholder organizations (community-based AIDS service organizations, Aboriginal organizations, ethnocultural organizations, researchers and professional associations) were also asked to provide their views on the balance among components in the Strategy. Interviews were conducted by telephone and responses were typically captured using a five-point scale. Overall, just over one-quarter of all respondents believe that the current balance in the Strategy is appropriate (i.e., 27 per cent indicating a four or a five on a five-point scale). Just over one-half believe that it is not appropriate (i.e., 54 per cent). The remaining 19 per cent of respondents were unable to comment on the appropriateness of the current balance. Analyses showed that forty-one per cent of those who were unsatisfied with the current balance thought there should be more research, in contrast to 36 per cent who thought there should be more treatment and support, and 32 per cent who thought there should be more prevention.[16]

Comparison of responses in Waves 1 (1995) and 2 (1997) of the Panel Study of individual stakeholders shows how views of the Strategy have evolved over time, providing a measure of its responsiveness to its external partners. Over this period, there is no significant change in the relatively low proportion of panellists who feel that the current balance in NAS-II, for example, between research, care, education, etc. is appropriate. As in Wave 1, a minority stated that the balance is appropriate. These results echo those found in the surveys in stakeholder organizations. Panellists in this study provided a number of suggestions to improve balance, with the largest category of comments relating to more focus on research, followed by comments about the need for more funding for education and prevention.

3.2 Desired Federal Roles

Respondents to the provincial/territorial survey were asked to discuss what they feel should be the future form of coordination and division of federal and provincial/territorial responsibilities for HIV/AIDS in Canada. While various suggestions were provided, all agreed that the federal government continues to have an important leadership role to play in HIV/AIDS. It was noted that the disease is increasingly concentrated in marginalized populations (e.g., injection drug users) and that the federal government has an important role in speaking for these groups. These groups are not "politically attractive" and are not generally well organized on this issue, and if the federal government does not take a lead, little would be done by the provinces/ territories. The federal government also has responsibility for Aboriginal peoples. Respondents therefore argued that the federal government must continue to take the lead in providing national coordination and leadership, in addition to providing funding. Many respondents suggested the federal government should retain its roles of establishing goals and priorities (in consultation with its partners), establishing research priorities (in consultation), conducting research, and disseminating information.

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[16] As this question permitted multiple responses, the percentages do not add up to 100.

Provincial respondents noted that care and treatment will continue to be a provincial/territorial responsibility. Some respondents argued that provinces/territories must take increased responsibility, with some activities being transferred to the provinces/territories. Some respondents felt that the provinces should be solely responsible for the collection of epidemiological data. Respondents from smaller provinces/territories, however, mentioned that they do not have the resources to conduct this activity without assistance and that it should remain a federal role.

Other areas which were identified by respondents as being important for the federal government to maintain its effort included:

- national policy leadership — policy analysis and development; guidelines and national standards;
- information generation and dissemination (e.g., activities such as epidemiological and surveillance research, the Clearinghouse, ATIN);
- regulatory aspects in which the federal government is mandated by law (e.g., therapeutic product approvals [blood and blood products, drugs, medical devices, tissues and organs, and vaccines], quality assurance for laboratory activities);

- ensuring universality; and
- education and prevention in Aboriginal communities.

The rise in HIV/AIDS infection in Aboriginal communities was a strong concern among key informants from all respondent groups. Federal activities were said to not sufficiently address HIV/AIDS in the Aboriginal population, although community awareness was perceived to have increased due to prevention and education. However, it was noted that HIV/AIDS has not been a high priority in many Aboriginal communities.

Respondents were divided on the role of the federal government in programs emphasizing direct service delivery or community-based programming such as ACAP. These areas, which have traditionally been the responsibility of the provinces, are seen by some as areas where the government could potentially reduce or withdraw its support. This view holds that the initial stages of the epidemic demanded an immediate and far-reaching program response to avert the rapid spread of the disease, a response which could not be assumed by the provinces at that time. Now, however, it is felt that there is a need to re-evaluate this requirement and for the provinces to assume their traditional responsibilities in this area. According to these key informants, provinces are better positioned (i.e., closer to the community) to provide the kinds of targeted, community-based programming that has proven to be most effective.

Other key informants at all levels were strong defenders of the federal role in community-based programming. They argued that:

- HIV/AIDS is distinguished from other diseases or health issues because it is a *pandemic*. The rationale for federal involvement in health issues that are, under other circumstances perhaps outside its jurisdiction, is stronger for HIV/AIDS.
- HIV/AIDS continues to carry a level of stigmatization that hinders research, prevention, treatment and care responses. Needle exchange programs and prevention research for marginalized populations such as IDUs are examples of efforts which would not likely attract the attention of provincial

governments or private sector/individual donations. Another example provided of federal leadership is in needle exchange programs. Cost-shared programs were vital in ensuring needle exchange programs, which are not popular politically, were implemented. The role of the federal government has been to legitimize this effort and highlight issues which local governments might be reluctant to pursue.

☐ According to some key informants, without federal funding, many community-based organizations would simply not survive. This would be particularly true in smaller provinces where federal funding is significant and provinces are not well-positioned to absorb the additional costs should the federal government withdraw financial support for these activities. It was suggested that equality of access to services would suffer.

This was confirmed by several provincial respondents, who felt that Health Canada, through its strong leadership role, has compelled their provincial/territorial government to assume part of the responsibility for HIV/AIDS programs. These respondents felt that any withdrawal of Health Canada would have a profound impact, and that provinces/territories would not assume any responsibility for activities Health Canada ceases to perform.

If there is a trend toward decreased federal funding for community-based activities, several respondents argued that there is a need for a transition period to allow organizations to seek other funding and to develop skills to improve sustainability through other activities.

Respondents at all levels also provided mixed comments on the role of the federal government in education and prevention activities, essentially stating that this is an areas where federal/provincial sharing and joint responsibility should be developed. The movement of the epidemic into more marginalized groups (e.g., IDUs, Aboriginal people) is seen as requiring targeted, community-based prevention activities. The provinces and local governments are viewed as having greater responsibility and capacity for these types of education and prevention activities. Closer connection to the communities affected is believed to yield more targeted and imaginative projects, though there may be a federal role in terms of broad education and prevention research and guidelines. There is also a continued, though less urgent, need for national awareness and education activities "to keep drumming the drum" among the mainstream population.

3.3 Continued Need for a National AIDS Strategy

There was a broad consensus among key informants from all respondent groups that there is a continued need for a national AIDS Strategy in Canada. Respondents noted, for example:

- Recent increases in the rate of HIV infection.
- The fragmentation of the epidemic among heterogenous populations, for example, young gay men, youth, Aboriginal people, and injection drug users. The highly varied needs of these groups require diverse and highly targeted strategies and new partnerships.
- There continues to be significant stigmatization and discomfort surrounding the disease. The absence of a coordinated, national strategy would undermine the level of attention and support, required to address the disease.
- The effectiveness of the recent combination therapies and lower levels of morbidity and mortality has raised a series of emerging issues which must be addressed. These issues include, for example, ongoing care and treatment (including dealing with drug resistance, drug interactions, and lifestyle issues), longer-term income security, and human rights in the workforce and elsewhere (e.g., travel).

Together, these issues clearly indicated to respondents the need for a national strategy in Canada to address HIV/AIDS. There is, however, a need for continuing discussion around the best means for achieving goals and the extent to which a strategy for HIV/AIDS can and should be integrated into broader areas of sexual health.

3.4 Duplication and Overlap

Within the federal government, the activities of NAS-II are generally viewed as complementary among themselves. Duplication and overlap do not pose a threat at this level given the division of responsibilities into the various activity or component areas. Although coordination and communications have been noted as an area for improvement, it was thought that groups engaged in similar activities or reaching similar populations communicate with each other to avoid overlap.

Synergy or complementary activities within Health Canada are actively pursued through the use of regular and ad hoc committees. The Departmental Aboriginal AIDS Committee (DAAC) and the Departmental AIDS Research Committee (DARC) for example, have been successful in developing collaborative efforts among the various branches and programs. As well, there is significant personal and informal coordination among programs. Programs within the HPPB, for example, have collaborated on a number of projects which cut across the various program areas.

Although some regions appear to have been more successful than others, both regional and national ACAP and MSB staff have worked together to reduce the potential for overlap. In some regions, partnership among these two players is still in its infancy, whereas in others, funding for programming is frequently shared between ACAP, ACTSP and MSB, and in some cases, the provincial health department.

The extent of overlap between NAS-II and the activities of provincial and municipal governments was also addressed by the key informants. The involvement of the federal government in HIV/AIDS-related health issues, particularly in the area of community-based activities, has the potential to duplicate the efforts of provinces and municipalities who hold the responsibility for these areas.

While some key informants believed that, at the theoretical level there is some potential for duplication, at the program level this does not typically occur. In smaller provinces such as in the Prairies and Atlantic Canada, the federal NAS funding is virtually the only source of financing available to non-governmental organizations, with provinces contributing only modestly or not at all to community-based activities. In the larger provinces — BC, Ontario, Quebec — provincial funding of HIV/AIDS activities is significant and far exceeds the federal contribution.

For community-based activities such as those funded under ACAP, duplication is avoided through the use of a peer review process. Provinces are represented on peer review committees to ensure that duplicate activities are not funded or, in some regions, Health Canada is represented on provincial AIDS funding committees and intergovernmental committees on Aboriginal people and AIDS. As well, the application process collects information on other sources of funding for projects. Finally, the roles and responsibilities of the different levels of government may be quite different. In some regions, the division between federal and provincial funding activities has the federal government providing project-based funding and the provincial government focusing on operational funding to community-based organizations.

In the survey of stakeholders, little overlap was observed among programs and services delivered by federal and provincial governments (i.e., 69 per cent indicated a one or a two on a five-point scale, where one means no overlap).

In terms of the research activities funded by the Strategy, the peer review process is again instrumental in ensuring that funding activities do not overlap or duplicate existing activities. Funded research must establish its importance or value and the peer review scrutinizes this against the available literature.

While respondents did not believe there was significant duplication between federal and provincial/municipal government activities, nor did they describe a great deal of synergy. NAS-II is best described as a federal, rather than national, strategy. As the international comparisons showed, other countries, especially Australia, have been better able to integrate and delineate areas of federal and provincial responsibility in HIV/AIDS, creating a truly national strategy.

At the provincial level, it was noted that Health Canada priorities (for research and project funding) do not always coincide with the priorities and needs at the provincial/territorial and local level. For example, representatives of a few NGOs suggested that organizations sometimes find themselves preparing proposals for projects that address a Health Canada priority for targeted funding, even though it is not necessarily an urgent priority in their community. These respondents suggested that provincial and territorial governments and organizations should have greater involvement in the identification of priorities and targets.

The Federal/Provincial/Territorial Committee has not played an effective leadership role in supporting a coordinated national strategy or promoting collaboration around data collection, policy development and program activities. The committee was dormant for a long period during the middle of the Strategy and has only recently begun to meet again on a regular basis. Moreover, while the F/P/T committee required one senior policy representative at the ADM level (or equivalent) from each participating jurisdiction, in reality, the membership of the committee is composed of individuals at the program level.

3.5 Coordination

The Mid-Term Review noted deficiencies in NAS in terms of coordination. At that time, the overall coordination of the Strategy was the responsibility of the National AIDS Secretariat. The Secretariat initially reported to the Associate Deputy Minister of Health, then to the Assistant Deputy Minister of the then Health Services and Promotion Branch. Since the Mid-Term Review was completed, the organizational structure of NAS has changed — coordination is now the responsibility of the HIV/AIDS Policy and Coordination Office which is now located within HPPB. (This reorganization appears to have been driven less by the mid-term evaluation and more by a trend within the department overall toward organizational simplification/streamlining).

Coordination continues to be a stubborn weakness in the Strategy. The AIDS Coordinators Committee is the primary vehicle for enacting the coordination role of the HIV/AIDS Policy and Coordination Unit. While the committee meets regularly, its activities are primarily in the realm of information sharing and exchange rather than strategic decision-making and discussion or policy planning for emerging issues. The committee lacks authority to deal meaningfully with resourcing issues across activities or to respond to emerging issues. The membership in the committee is not appropriate for all. While efforts to coordinate the science and program aspects of the Strategy have yielded some improvements, the relationship could be closer still.

Although the mandate of the AIDS Secretariat was to extend to the international aspects of HIV/AIDS, no specific funds were allocated to this function, and coordination of Canada's international effort has been poor. According to key informants, it has been hampered by a lack of proactive effort on the part of the Policy and Coordination office and a lack of communication between LCDC and CIDA around the issue of research support.

A number of challenges or barriers to a coordination were mentioned:

- ☐ ***Organizational location.*** The location of the policy and coordination unit within the HPPB presents challenges to coordination *across* branches. It was argued that the unit cannot maintain a "strategy-wide" perspective when it is identified with HPPB. Moreover, the fragmentation of authority across different branches means that authority is also fragmented with different senior managers holding responsibility for different aspects of the Strategy.
- ☐ ***Frequent turnover*** of staff within the policy and coordination unit.
- ☐ ***Satisfying the needs of the bureaucracy*** for briefing note and reporting materials is demanding and threatens to dominate the efforts of the unit, minimizing the role of coordination and policy analysis and development.

- ☐ ***Unclear or limited mandate for the unit.*** Neither the Policy and Coordination Office nor the AIDS Coordinators Committee have any financial authority over the components of the Strategy. As well, the mixing of coordination/policy development functions with the role of monitoring and financial accountability has posed challenges for the unit and is perceived to be threatening to other programs.
- ☐ ***Significant differences in the working culture*** among the various branches and organizations which compose the Strategy.

Some frustrations were expressed by regional Health Canada respondents about a perceived lack of communication between headquarters and the regions. While there is significant exchange around the ACAP (regional and headquarters staff meet three times of a year to conduct strategic planning and information sharing), regional staff are often not well-informed about other Health Canada activities occurring locally. Some provincial partners do not have a good understanding of contact points for different elements of the Strategy.

Coordination appears to stakeholder organizations to be a weak spot in the national strategy. Only one-quarter of respondents believe that the overall Canadian response to HIV/AIDS is well coordinated (i.e., 26 per cent). In contrast, professional organizations and ethnocultural organizations sampled were almost twice as likely to believe that the overall response was well coordinated (i.e., 40 and 46 per cent respectively).

Despite these difficulties, the results from the panel survey of stakeholders indicates a marginally significant perceived improvement in the coordination of the Strategy over time ($t(65)=-1.86$, $p < .10$). Moreover, the perceived adequacy of NAS-II's implementation has improved significantly over time ($t(65)=-3.83$, $p < .01$).

No clear alternative to the current coordination structure that emerged from the key informant interviews. Some of the suggestions included:

- ☐ establishment of an AIDS coordinating committee composed of a limited number of senior representatives (e.g., branch heads) with an expanded mandate to steer the Strategy (i.e., power to make resourcing decisions);
- ☐ establishment of an independent organization at arms length from the bureaucracy (similar to the Canadian Centre for Substance Abuse or the National Council on Welfare); and
- ☐ formation of a national governing council with representation from the federal government, provincial governments, national non-governmental organizations with shared responsibility for steering the strategy.

The international comparisons showed that in many countries a tendency toward decentralization and horizontal integration of HIV/AIDS programs is occurring. Integration of STD and HIV/AIDS programs (i.e., "mainstreaming") is regarded as a central issue in this tendency, as are expanded links to primary care and social services.

Clearly, a renewed coordination function for the Strategy must be perceived to be credible by participants. An expanded mandate which focuses on policy development and decision-making must also be accompanied by meaningful participation of the various programs which compose the Strategy.

CHAPTER

4 SUCCESS OF THE NATIONAL AIDS STRATEGY

This chapter examines the success of the Strategy as a whole and of its constituent components. Both expected and unexpected impacts are examined.

4.1 Objectives Achievement and Success Areas

Overall, NAS-II has been a partially effective strategy in achieving its objectives:

- *Stopping the spread of HIV.* The Strategy is seen as having been partially successful in terms of its first objective. The rate of HIV infections decreased between 1985 and 1991, indicating the success of education and prevention activities targeted at the populations at risk at that time (though exhaustion of the susceptible population could also explain some of this decrease) as well as virtual elimination of transmission through the blood supply. The Strategy was responsible for marshalling resources (model development, surveillance) to target prevention activities. The Strategy raised broad awareness of the disease and maintained a public policy focus on the disease. However, indications are that the rate of HIV infection has increased subsequently during the period covered by NAS-II, particularly among young gay men and injection drug users (IDUs). Similarly, the rate of infection among Aboriginal people has been increasing and concern exists that the rate of infection has not yet peaked among this population.

- ***Providing care, treatment and support.*** As a result of community-based programming such as ACAP, NAS-II is believed to have contributed to the development and mobilization of an infrastructure of non-governmental organizations offering support to the HIV/AIDS community. Health professionals have been sensitized and educated to deal with HIV/AIDS patients. According to key informants, this network of care and support organizations has fostered a caring community of professionals and volunteers and improved the quality of life for persons living with HIV/AIDS. This network extends beyond the key centres (Montreal, Toronto and Vancouver) to smaller and more remote centres, allowing people with HIV/AIDS to have access to care, treatment and support in their communities. NAS-II has also stimulated the development of HIV/AIDS strategies at the provincial level.

  Specialized care and treatment for HIV/AIDS is provided to Aboriginal people via the provincial health systems, but is not available on- reserve through the medical services provided by MSB to Status First Nations and Inuit people. MSB programs and services regarding specialized HIV/AIDS care direct individuals to treatment programs and clinics off-reserve. There is a need to establish some type of infrastructure on-reserve in order to accommodate individuals, at various stages in their disease, who wish to return home to their reserves both for care as well as to die.

- ***Searching for effective vaccines, drugs and therapies.*** Mortality and morbidity rates among people with HIV/AIDS have decreased considerably during the life of the Strategy. This is attributed to the development of new treatment regimens. While this is the product of international research efforts, the Canadian contribution has been significant. The development of 3TC is widely believed to be an important Canadian "success story" (although it was pointed out that these claims may be somewhat overstated). The approval processes for new therapies are also seen as effective. The Strategy has also been successful in expanding the knowledge base through comprehensive and reliable AIDS surveillance and epidemiological data, although challenges remain for HIV surveillance, especially among high-risk groups.

In addition to the effectiveness of the Strategy in terms of meeting its objectives, many important indirect impacts of NAS-II were noted. These include:

- Contribution and support for active consumerism and greater participation of patients in their own care and treatment.

- Legitimization of a multi-sectoral approach to dealing with disease. These types of approaches and notions about health and treatment which have been pioneered by HIV/AIDS are proving transferable to other groups and diseases.

- ☐ The development of an infrastructure for addressing the epidemic. It is also seen as doubtful that many organizations could have provided the focused programming they did on AIDS issues without NAS-II funding.
- ☐ Raising awareness of the disease and dispelling some of the myths associated with it. Efforts have been made to "put a face on AIDS" and move away from scare tactics in communicating about the disease.
- ☐ The mobilization of volunteers.

Areas where the Strategy has been less successful, according to key informants are:

- ☐ ***HIV/AIDS in the Aboriginal community.*** The Strategy has generated little knowledge about the epidemiology of HIV/AIDS in the Aboriginal community. That ethnicity is not always required or captured on reporting forms has contributed to a lack of information. A focus on research with Aboriginal people is also required to inform dosing and treatment strategies for this population. Community-based responses to the disease among this group have also been weak. Major challenges to effective intervention remain, including the lack of priority given to HIV/AIDS in the communities themselves, and the other health and social problems facing many of their members.
- ☐ ***International effort.*** Several respondents noted that the Strategy lacks a coherent and visible international strategy that is well-integrated with other components of the Strategy. The federal government is perceived to have played a relatively weak role in terms of contributing to improvement of the HIV/AIDS situation internationally. This was a criticism of the Strategy noted in the Mid-Term Review and continues to be a weakness in the overall Strategy. CIDA, which is most directly involved in international efforts, is perceived to operate quite independently from the rest of the Strategy.
- ☐ ***Comprehensive HIV database.*** Information on the incidence and prevalence of HIV is crucial for planning care, treatment and support and for anticipating the need for and targeting of education and prevention activities. Although data on HIV cases are now being collected, these data are not yet available.
- ☐ ***Interdepartmental collaboration.*** There have been a number of projects carried out under NAS-II which have involved interdepartmental

cooperation. For example, the HIV/AIDS Policy and Coordination office, through AEPU, undertook a cooperative project to provide training to customs and immigration officers. Yet, interdepartmental coordination is an area which could have been more successful, according to key informants, and which should receive a greater focus in the future. The Mid-Term Review of NAS-II also noted that the Interdepartmental Committee on Human Rights and AIDS, the formal mechanism for interdepartmental coordination, was largely inactive and had little impact on the operation of the Strategy. The issue of HIV/AIDS should be better integrated across a broader spectrum of policy issues. Departments which should be more involved in HIV/AIDS include: Human Resource Development Canada (e.g., income security issues, work-related issues), Revenue Canada, Indian and Northern Affairs (on-reserve social services) and Canada Mortgage and Housing Corporation (e.g., housing). Communications across jurisdictions was also identified as a weak area.

- ☐ ***Federal/provincial collaboration.*** The Federal/Provincial/Territorial Committee did not meet for some time and did not play an active role. This may have contributed to the less active stance of some provinces in assuming responsibility for HIV/AIDS and inequalities between provinces in accessibility of services.
- ☐ ***HIV/AIDS in the IDU population.*** The spread of HIV/AIDS in the injection-drug user population was voiced many times as a cause for concern. There are many success stories and lessons which have been learned in treating this population — street youth, needle exchanges and mobile medical clinics. This is seen as an area where the Strategy could have responded more quickly to address the needs of this difficult group.
- ☐ ***Private sector.*** Several respondents noted that NAS-II has not been successful in securing private sector support and contributions for Strategy activities and projects. Recognizing that HIV/AIDS may not be appealing for many corporations, there is a need to pursue leveraging opportunities. Efforts by Health Canada to encourage private sector involvement were noted in the documentation reviewed. For example, Health Canada, in collaboration with HIV/AIDS community groups and the private sector, initiated the development of a "business case". This "case" will present the rationale and economic impact of including Canadian businesses in HIV/AIDS related activities. This "case" will be of use to NGOs when approaching the private sector for support, as well as to the corporate sector who can use it, for example, when developing an HIV/AIDS workplace policy.
- ☐ ***Evaluation.*** The emphasis on ongoing monitoring and evaluation of NAS-II funded projects has been weak. The effectiveness and cost-effectiveness of many of the projects and components of the Strategy cannot be determined except anecdotally. Although ACAP has been collecting evaluative

information from projects, there is little evidence that this information is synthesized and used as a management tool.

Respondents acknowledged that it is difficult to know with absolute certainty what would have happened to the HIV/AIDS epidemic in Canada if there had not been a NAS-II. There is a widespread belief, however, that NAS-II has slowed the spread of HIV/AIDS among men who have sex with men, and that access and quality of care, treatment and support would have been much poorer.

In the two-wave panel study of stakeholders, NAS-II is rated significantly higher on its overall effectiveness at Wave 2 than Wave 1 ($t(72)=-3.79$, $p <.05$), with almost half of respondents (44 out of 94) giving the two highest ratings on the five-point scale measuring effectiveness. Perceived adequacy of its products and services has also increased from Wave 1 to Wave 2 ($t(68)=-2.39$, $p <.05$).

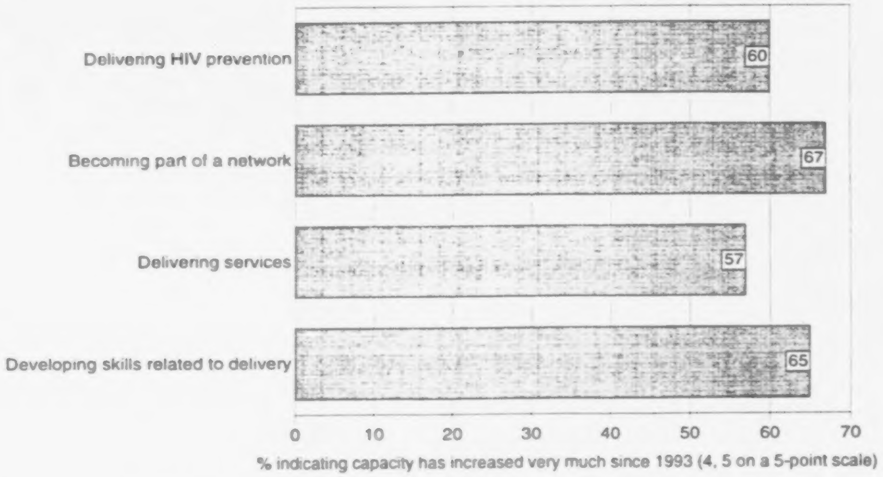
4.2 Capacity Enhancement

Stakeholder organizations were asked a series of questions regarding their involvement in the Strategy, whether their capacity to deliver services had increased, to what extent this increase could be attributed to the federal Strategy, and if it were sustainable in the absence of federal funding.

(a) Community-Based Groups

Community-based groups were asked how much the capacity of their group had increased since 1993 in a number of areas. A majority (57 to 67 per cent) responded that their capacity had increased a great deal in four keys areas (i.e., indicating either a four or a five on a five-point scale). These findings are displayed in Exhibit 4.1.

EXHIBIT 4.1
Increases in Capacity in Four Key Areas: Community-Based Groups



Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey. (n=60)

The greatest improvements in capacity occurred with respect to becoming part of a network of organizations working to stop the spread of HIV (i.e., 67 per cent indicating either a four or a five on a five-point scale). Relatively greater increases were also seen in the capacity to develop the skills of people who deliver services to people living with HIV/AIDS (i.e., 65 per cent) and in the capacity to deliver HIV prevention to vulnerable or high risk individuals (i.e., 60 per cent). Just over one-half of community-based organizations identified an improved capacity to deliver services to people living with HIV/AIDS (i.e., 57 per cent). However, fewer than half (47 per cent) of the groups that reported improved capacity identified the federal AIDS Strategy as a significant factor in the improvement.

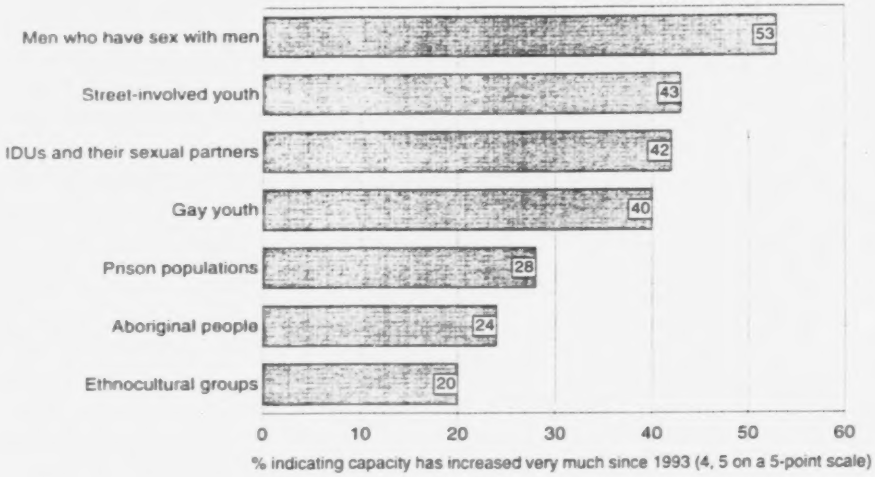
The extent to which capacity in four key areas had increased since 1993 was explored with community-based groups. These were: planning programs; implementing programs; coordinating activities; and mobilizing community resources. Nearly 60 per cent of groups responded that their capacity had increased very much in the first three areas (i.e., 57 per cent in planning programs, 58 per cent in implementing programs, and 60 per cent in coordinating activities). In contrast, only 40 per cent of these groups saw that their capacity to mobilize community resources had improved. As before, just under half (49 per cent) of the groups attributed the overall improvements to the federal AIDS Strategy.

Respondents were also asked if their increased capacity had helped them to reach a number of target groups. The proportion indicating that increased capacity had helped their efforts to reach target groups very much (i.e., a four or a five on a five-point scale) ranged from a low of 20 per cent to a high of 53 per cent. These figures are presented in Exhibit 4.2 and should be interpreted in light of the fact that different community-based groups will target different groups of individuals and that the categories may not be mutually exclusive.

Increased capacity appears to have had the greatest impact on improved efforts for those groups trying to reach men who have sex with men; just over one-half of respondents indicated that increased capacity had helped them reach this target group. (Case Study No. 1, on page 45, provides an example of a community-based organization targetting men who have sex with men.) An improvement was also noted by about 40 per cent of groups trying to reach youth (43 per cent targeting street-involved youth, 40 per cent targeting gay youth) and 42 per cent of groups trying to reach intravenous drug users (IDU) and their sexual partners. This finding is somewhat at odds with the epidemiological data used previously, which suggest that this target group is not experiencing effective prevention. Increased capacity had limited effect on helping organizations reach prison populations (i.e., 28 per cent), Aboriginal people (i.e., 24 per cent) and ethnocultural groups (i.e., 20 per cent).

Community-based organizations were asked about the extent to which the federal strategy had provided them with useful resources and tools to both stop the spread of HIV/AIDS as well as to deliver services for people living with AIDS. A little more than four in ten responded that the federal strategy had in fact provided them with

EXHIBIT 4.2
Increases in Capacity to Reach Target Groups: Community-Based Groups



Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey. (n=60)

useful resources and tools to a great extent, with respect to both areas (i.e., 42 per cent and 43 per cent indicating a four or a five on a five point scale for stopping the spread of HIV/AIDS, and for delivering services respectively).

Community-based groups were asked about the proportion of their current activities they would be able to carry on if the federal government were to significantly reduce (almost eliminate) its role and resources. Community organizations state that they would be, on average, able to carry out about one-half of their activities if federal funding was either cut in half or ceased altogether. It should be noted that there was significant variation among groups. Nearly one-quarter (i.e., 23 per cent) responded that they would be able to carry on 75 to 100 percent of their activities, whereas about one-third (i.e., 36 per cent) indicated that they would be able to carry on 50 to 75 per cent of their activities without federal funding. A little over one in ten (i.e., 11 per cent) would

LESSONS LEARNED CASE STUDY No. 1:

Healthy Choices Project, Sudbury

The Healthy Choices Project in Sudbury, Ontario is run by ACCESS, The AIDS Committee of Sudbury (Le comité du SIDA de Sudbury), a bilingual community-based organization. This project demonstrates effects of NAS-II support to community-based groups.

ACCESS has been funded under both Phase I and Phase II of NAS, and has been in existence since 1989. As a result of the homophobic environment in the Sudbury region, a need for education and support was identified, and the AIDS Committee of Sudbury was created. Healthy Choices, run by ACCESS, conducts three main programs: 1) Man to Man: to prevent further spread of HIV among men who have sex with men; 2) Positive Living: to develop health promotion activities for PLHAs living in the Sudbury and Manitoulin District; and 3) Service Providers in the Community: to create a supportive social environment within the Sudbury and Manitoulin District for PLHAs, for people at risk of HIV infection, care givers, families and friends.

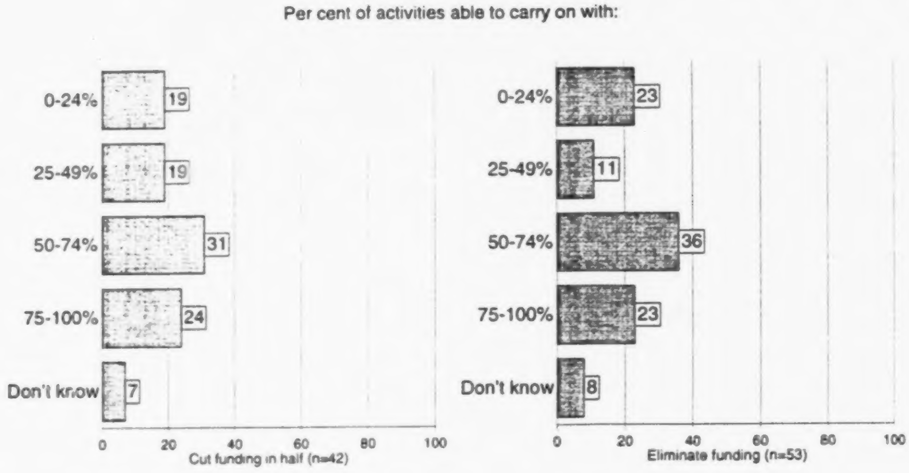
The Healthy Choices project is considered to be innovative due to the targeted nature of the services (gay and bisexual men, people living with HIV/AIDS, and the community as a whole in terms of attitudes toward homosexuality). As well, its bilingual activities are centred around prevention and education activities. Healthy Choices also conducts regular evaluations of all its activities. Its team approach is also regarded as innovative.

Several challenges were encountered during implementation of the Healthy Choices project: the target group was particularly hard to reach as some did not want to be helped and many did not want to be identified as homosexual and/or HIV positive; it was difficult to win over the gatekeepers to the gay/bisexual community; less than a year after project start-up, another local community-based organization targeting to homosexual men collapsed resulting in a gap in service delivery to this population group; unfortunately, much of that organization's activities fell beyond the scope of the Healthy Choices project; and documentation was also considered to be a challenge, as the target group does not want to be identified in literature and reference materials.

Healthy Choices has been successful, not only by its longevity, but also by the increasing number of requests for information and support it receives. Moreover, the project makes use of numerous other NAS-II resources, including the CPHA National AIDS Clearinghouse.

be able to carry on 25 to 50 per cent of activities, while just over one-fifth of respondents (i.e., 23 per cent) would be able to carry on less than 25 per cent of their activities (Exhibit 4.3).

EXHIBIT 4.3
Impact of Funding Cuts on Activities
(Community-Based Groups)



Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey.

(b) Professional Associations

On the issue of increased capacity since 1993, respondents' experiences were divergent. Equal proportions reported little or no increases in capacity and significant increases in the capacity of the professionals in their respective organizations to deliver services to people living with HIV/AIDS (i.e., 44 per cent responded that capacity had not increased a lot, 44 per cent responded that capacity had increased a great deal, and the remaining 12 per cent did not know). Only one-quarter attributed their increases in capacity to the federal Strategy (i.e., 28 per cent indicating a four or a five on a five-point scale) and very few respondents believed that this capacity was sustainable in the face of a significant reduction (i.e., almost elimination) in the federal role and resources (i.e., eight per cent). As a caveat, it should be noted that non-response was fairly high on the two latter issues (i.e., 36 per cent and 20 per cent respectively) and may be indicative of low levels of knowledge regarding the impact of the federal Strategy. Findings should be interpreted accordingly.

The issue of capacity was explored in more detail with respect to four specific areas. As with service delivery, capacity has similarly not increased with respect to planning programs, implementing programs, mobilizing professional resources, and coordinating activities. Only a minority of stakeholders from professional associations believed that their capacity had increased to plan programs (i.e., 36 per cent), to implement programs (i.e., 28 per cent), to mobilize resources (i.e, 32 per cent) and coordinate activities (i.e,. 44 per cent).

Although professional associations observed only moderate increases in capacity in these four areas, unlike the increases observed in service delivery, a slight majority responded that these increases were attributable to the existence of the federal Strategy (i.e., 54 per cent). Similarly, a majority believed that the Strategy has improved services (in general) to people living with HIV/AIDS to a relatively great extent (i.e., 56 per cent indicating a four or a five on a five-point scale).

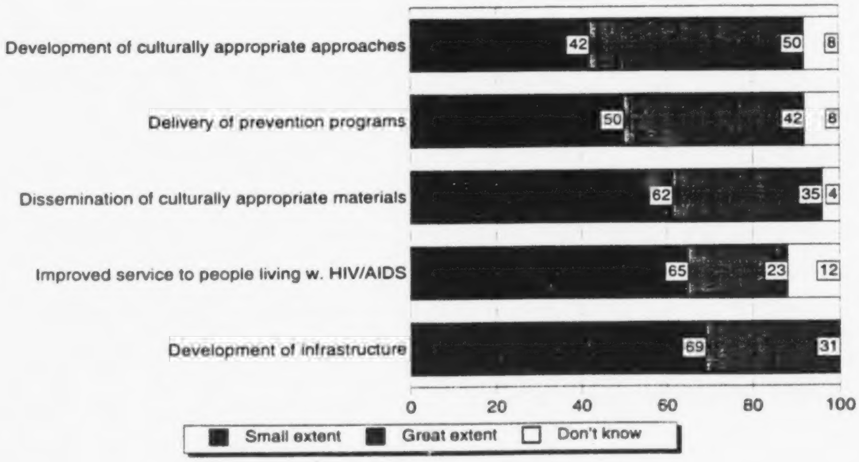
In view of the fact that resources have become available from more sources since 1993, professional associations were asked about the proportion of their current activities they would be able to carry on if the federal government were to significantly reduce (almost eliminate) its role and resources. Professional associations would, on average, be able to carry out about 58 per cent of their activities in the absence of federal funding, but with significant variation among the different associations. Less than one-half would be able to continue with 75 to 100 percent of their activities (i.e., 44 per cent). Twelve per cent responded they would be able to carry on 50 to 75 per cent of activities, eight per cent would be able to carry on 25 to 50 per cent of activities, while 32 per cent responded they would only be able to carry on 0 to 25 per cent.

(c) Ethnocultural Organizations

Ethnocultural organizations were posed a number of questions relating to the federal Strategy. In most of the areas probed, more than half the ethnocultural organizations surveyed saw the federal Strategy as having only a small impact on their issues or concerns. These findings are displayed in Exhibit 4.4. The Strategy had the least impact on these organization's ability to develop infrastructure, mobilize community resources and disseminate appropriate information. This may be partially explained by the fact that nearly two-thirds (i.e., 65 per cent) of the organizations perceived that NAS-II had not engaged their respective ethnocultural communities as a partner in the Strategy. In spite of this, one-half of organizations indicated that the federal Strategy had helped communities to develop approaches to dealing with HIV/AIDS to a great extent (i.e., 50 per cent indicating a four or a five on a five-point scale). A similar proportion also attributed increases in their capacity to the federal Strategy (i.e., 48 per cent indicating a four or a five on a five-point scale).

Ethnocultural organizations were also asked how much the capacity of their group had increased since 1993 to plan and implement programs, to coordinate activities and to mobilize community resources. With respect to activities relating to planning and coordination, at least one-half of the organizations reported that their capacity had increased a great deal (i.e., 54 per cent and 50 per cent, respectively, indicating a four or a five on a five-point scale). Somewhat smaller proportions observed significant increases in activities relating to implementing HIV/AIDS programs and mobilizing community resources (i.e., 42 per cent and 31 per cent respectively). About one-half of respondents believed that the federal Strategy had played a significant role in increasing this capacity (i.e., 48 per cent indicating a four or a five on a five-point scale).

EXHIBIT 4.4
Impact of Strategy on Ethnocultural Organizations

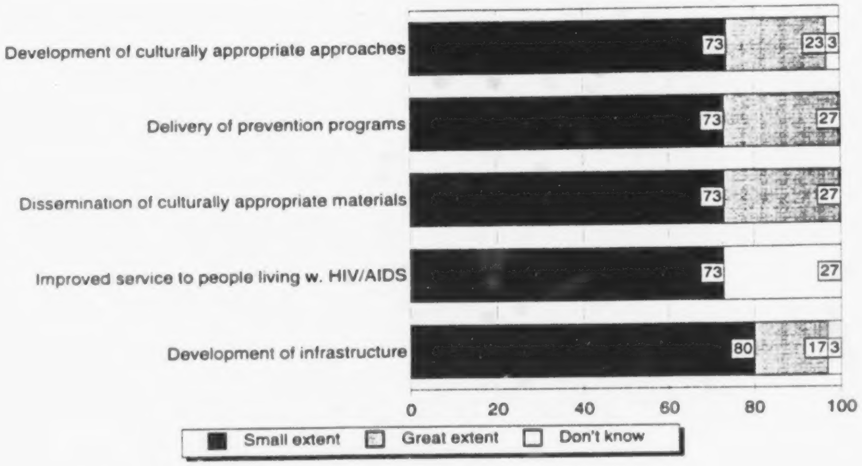


Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey. (n=26)

(d) *Aboriginal Organizations*

Aboriginal organizations were posed a number of questions relating to the impacts of the federal Strategy in several areas. Almost seven in ten (i.e., 68 per cent) of these organizations targeted Aboriginal Canadians who live on-reserve. Generally speaking, the Aboriginal organizations saw the federal Strategy as having limited impact on their issues or concerns; at least three-quarters of respondents indicated that the Strategy had little or no impact on the capacity of Aboriginal groups to respond to the epidemic in the key areas shown in Exhibit 4.5. Eight in ten Aboriginal groups surveyed saw the Strategy as having no impact on their community's capacity. This belief is likely to have been reinforced by a perception of exclusion: nearly three-quarters of respondents did not feel that NAS-II had engaged their Aboriginal community as a partner in the Strategy (i.e., 73 per cent indicating a one, two or a three on a five-point scale).

EXHIBIT 4.5
Impact of Strategy on Aboriginal Organizations



Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey. (n=30)

Aboriginal organizations were also asked how much the capacity of their respective groups had increased since 1993 to plan and implement programs, to coordinate activities and to mobilize community resources. In all four areas, at least two-thirds of organizations responded that there had been little or no increase (i.e., a one, two or three on a five-point scale) in their capacity: 67 per cent indicated little or no impact on coordinating activities, and 70 per cent, 73 per cent and 83 per cent on planning HIV/AIDS programs, implementing HIV/AIDS programs, and in mobilizing community resources respectively. Not surprisingly, given previous responses, few respondents saw the federal Strategy as having much impact in those areas where there had been some increases in capacity (i.e., 37 per cent indicating a four or a five on a five-point scale).

The opinions of Aboriginal organizations were also solicited with respect to the Medical Services Branch (MSB) of Health Canada and the AIDS Community Action Program (ACAP). Although MSB supports on-reserve initiatives and ACAP supports off-reserve initiatives, there were no discernible differences between respondents answering with respect to MSB or ACAP, and Aboriginal organizations responding noted that the distinction between on- and off-reserve populations is not always clear.

Respondent ratings on these topics were not encouraging. For example, the epidemiological data on Aboriginal Canadians were not perceived to be useful by more than one-half of responding Aboriginal organizations (i.e., 57 per cent indicating a one, two or three on a five-point scale). An even greater proportion felt that the prevention and education HIV/AIDS programs of the MSB and ACAP were not at all effective or only moderately effective (i.e., 64 per cent). Awareness of the use of HIV antibody testing services appears to be low; although nearly two-thirds felt that the HIV antibody testing services were not being used all that much, the remaining 36 per cent did not know.

Overall, the Strategy was felt by the Aboriginal groups surveyed to have had little success in enhancing capacity in Aboriginal communities. Little is perceived to have been accomplished to stop the spread of HIV among Aboriginal people. The perceived track records of both MSB and ACAP are similarly discouraging with respect to reaching people in communities and helping to provide services to community members living with HIV/AIDS. More than three- quarters of respondents felt that neither MSB nor ACAP have been doing a good job of reaching people in the communities and more than two-thirds felt that they have not helped their respective communities to provide services to community members living with HIV/AIDS (i.e., 79 and 68 per cent respectively indicating a one, two or three on a five-point scale).

(e) Pharmaceutical Firms

The evaluation attempted to contact a sample of ten key informants from the pharmaceutical sector, nominated by knowledgeable experts, to obtain their views. As only two of those contacted agreed to be interviewed, these results are not reported.

In general, those contacted stated that they did not feel sufficiently engaged in the Strategy to comment.

(f) Panel Study Respondents

In the two-wave panel study of stakeholders, NAS-II is rated significantly more highly at Wave 2 for the extent to which it has helped panellists inform other organizations about their results and findings (t(88)=-3.44, p <.001). The Strategy is also rated more highly at Wave 2 for helping panellists make their services more accessible (t(81)=-2.10, p <.05). At Wave 2, about half of the 94 panellists (48) state that NAS-II has improved their ability to conduct a range of services, as compared to 36 of these same respondents at Wave 1. Moreover, at both Waves 1 and 2, a majority of panellists stated that there would be a negative impact on their future activities if NAS-II products and services ceased to be available.

(g) Views of People Living with HIV/AIDS on the National AIDS Strategy

Respondents to the survey of people living with HIV/AIDS were asked to provide their views on the national effort.

When asked how much they feel is being done in Canada to help those living with HIV/AIDS, over half feel that "some" is being done (59 per cent) with 17 per cent being of the opinion that a lot is being done. Only five per cent are of the opinion that everything possible is being done. Seventeen per cent feel that nothing or almost nothing is being done.

Seventy-nine per cent of respondents had heard of the National AIDS Strategy. There is a difference when these findings are categorized according to when respondents were diagnosed with HIV. Respondents diagnosed prior to 1993 were more likely to have heard of the National AIDS Strategy (85 per cent) than were those diagnosed as of 1993 (71 per cent).

4.3 Research Effectiveness

As Tables 4.1 and 4.2 show, grant-based research funding from the Medical Research Council and the National Health Research and Development Program have totalled over $8 million per year during the period covered by NAS-II. Funding provided by both organizations is weighted toward basic and clinical sciences, with research on epidemiological, social or behavioral aspects of HIV/AIDS receiving less funding. This is similar to a previous study of HIV/AIDS research funding from 1984-85 to 1994-95.[17]

Key informants at all levels were asked to assess the effectiveness of federal research and development activities in contributing to knowledge about HIV/AIDS. Respondents were in strong agreement that federal research and development activities have been effective and useful in improving programs. Research and development activities are particularly helpful for smaller provinces/territories, which do not have sufficient cases or resources to warrant their own research. A number of respondents noted that research on specific populations (e.g., intravenous drug users, pre-natal screening) have been helpful and have assisted them in addressing these populations. Representatives of AIDS organizations noted that where it has been undertaken, ACAP-sponsored research and evaluation has had a positive impact on the quality of their initiatives.

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17. Turpin Consultants (1996). Canada's response to HIV/AIDS: A profile of research funding 1984-85 to 1994-95.

TABLE 4.1
HIV/AIDS Grant Research Funding, Medical Research Council (MRC) 1992/93 to 1996/97*
($000) and (No. of projects)

Research Area	YEAR					
	1992/93	1993/94	1994/95	1995/96	1996/97	1997/98
HIV pathogenesis	1,388.33 (20)	2,021.18 (25)	1,844.08 (21)	1,492.80 (18)	1,046.77 (14)	(data non available)
Treatment	529.26 (8)	512.98 (9)	430.88 (6)	355.83 (4)	259.85 (5)	(data non available)
Epidemiology/social/behavioral	439.03 (1)	564.03 (2)	439.03 (1)	349.02 (1)	339.25 (1)	(data non available)
TOTAL	**2,356.62** **(29)**	**3,098.19** **(36)**	**2,713.99** **(28)**	**2,197.07** **(23)**	**1,645.87** **(20)**	--

* Note: The figures do not include training and career awards or university-industry grants. Also, in 1996/97, an additional $1.5 million was transferred to NHRDP as part of the NHRDP/MRC Collaborative Initiative on AIDS Research (which is included in the NHRDP figures).

Source: Data provided by Medical Research Council, 1997.

TABLE 4.2
National Health Research and Development Program: HIV/AIDS Funding
(Grants and Career Awards, 1992/93 to 1997/98)

Research Area	YEAR					
	1992/93	1993/94	1994/95	1995/96	1996/97	1997/98
Number of projects	(data non available)	123 (39 new)	164 (82 new)	165 (38 new)	150 (33 new)	105 (1 new)
$ (000)	--	5,710.00	5,860.00	7,090.00	7,850.00	4,940.00

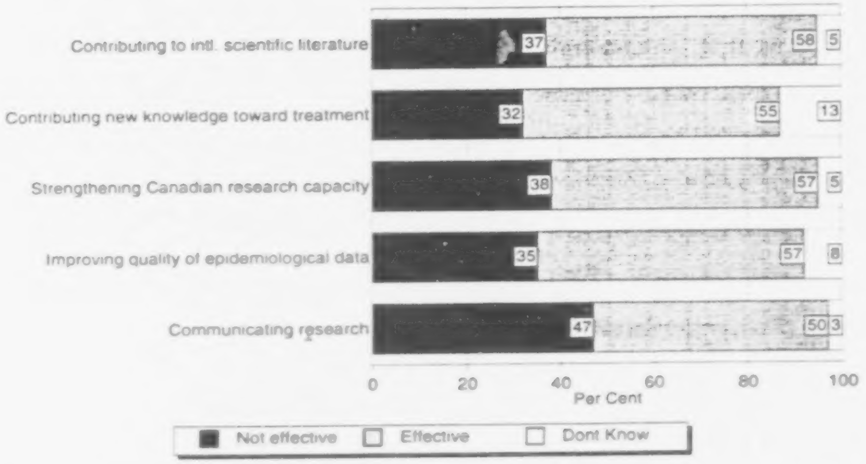
Source: Data provided by National Health Research and Development Program, 1997.

A sample of 60 Canadian HIV/AIDS researchers in universities and hospitals was posed a series in-depth questions concerning the overall Canadian research effort. Respondents were asked to rate the relative effectiveness or ineffectiveness of research and development associated with the national Strategy in a variety of areas. The top five areas in which research and development activities were judged to be particularly effective are displayed in Exhibit 4.6 and include the following:

- contributing to the international scientific literature on HIV/AIDS;
- contributing new knowledge toward development of effective drug treatment;
- strengthening the Canadian HIV/AIDS research capacity;
- improving the quality of epidemiological data on HIV/AIDS in Canada; and
- communicating research results.

Case Study No. 2 on page 59 on the Vancouver Lymphadenopathy Study, illustrates a successful NAS-II funded research program.

EXHIBIT 4.6
Five Most Effective Areas in Research and Development According to HIV/AIDS Researchers



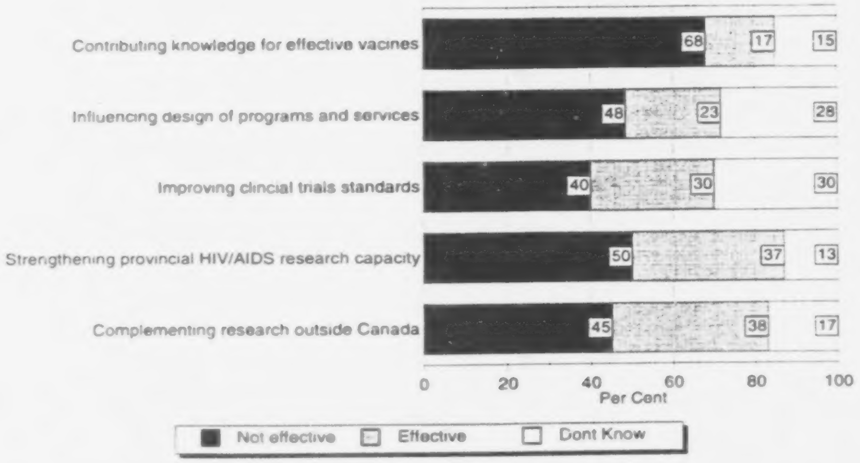
Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey.

(n=60)

The areas in which research and development activities associated with the Strategy were least effective are similarly presented in Exhibit 4.7. It should be noted that non-response to these questions was fairly high, likely reflecting a general lack of knowledge among respondents regarding the effectiveness of the research effort. Despite a lack of awareness, consensus is quite high regarding the ineffectiveness of research activities to contribute new knowledge toward the development of vaccines. Awareness is lowest regarding the influence of research and development on the design of programs and services. This may be indicative of a lack of communication among researchers and the end-users of their research activities, as found in the Mid-Term Review.

EXHIBIT 4.7

Five Least Effective Areas in Research and Development According to HIV/AIDS Researchers



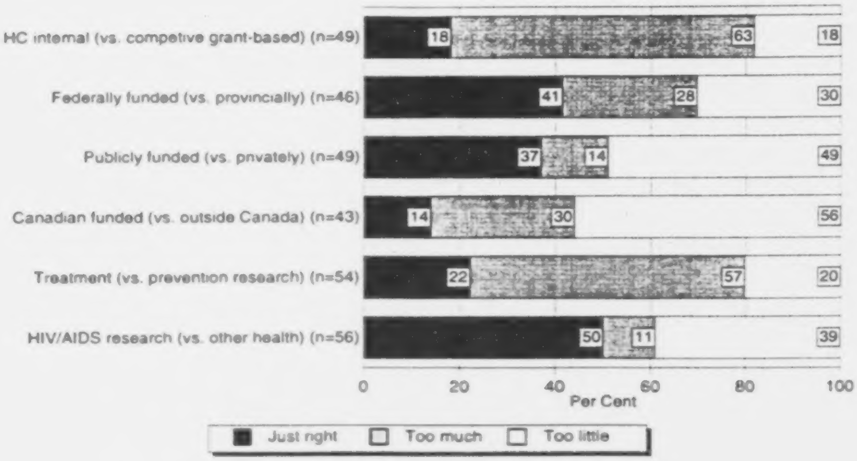
Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey. (n=60)

The current balance between several aspects of HIV/AIDS research in Canada was explored with researchers. Pairs of alternative funding mechanisms were presented and respondents were asked whether the balance between the two alternatives was about right, if there was too much or not enough research. As displayed in Exhibit 4.8, researchers generally felt that there was:

- too much internal Health Canada research (and not enough competitive grant-based research);
- too much privately funded (and conversely not enough publicly funded research);
- too much research funded from outside Canada (and not enough funded from within Canada); and
- not enough research on prevention (and conversely, too much on treatment research).

Case Study No. 3 (on page 60), of a vaccine research program, illustrates an internal Health Canada research program.

EXHIBIT 4.8
Balance Among HIV/AIDS Research Alternatives
(HIV/AIDS Researchers)



Source: Ekos Research Associates, Evaluation of NAS-II, 1997, Stakeholder Survey.

(n=60)

In addition to the issue of the balance of research activities, survey respondents were also asked a number of questions concerning Canada's two main granting agencies in this area, the National Health Research and Development Program (NHRDP) and the Medical Research Council (MRC). Respondents were asked the extent to which NHRDP's AIDS research grant programs have generated new knowledge about such issues as HIV pathogenesis (basic disease processes), education and prevention (transmission of the disease) and care, treatment and support. Respondents were of the view that NHRDP's AIDS research programs had generated new knowledge about HIV pathogenesis (i.e., 50 per cent indicating a four or a five on a five-point scale), but were less convinced of their ability to generate new knowledge about education and prevention (i.e., 35 per cent) or care treatment and support (i.e, 30 per cent).

LESSONS LEARNED CASE STUDY No. 2:

Vancouver Lymphadenopathy-AIDS Study (VLAS)

The Vancouver Lymphadenopathy-AIDS Study (VLAS) is a research program funded by the National Health Research and Development Program. The general objective of the research "has been to contribute to our understanding of the natural history of HIV infection, of the epidemiology of HIV and its modes of transmission and of the etiology of AIDS and its related clinical outcomes". It is an example of successful research efforts supported by NAS-II.

Using a cohort or longitudinal methodology, the VLAS has followed a large number of homosexual men, both HIV positive and HIV negative, since the early 1980's, beginning even before the HI virus was identified. In total, about 1,000 homosexual men have been recruited into the study; 729 between 1982 and 1984 and 271 men between 1986 and 1987. More recently, in 1993 a new vanguard cohort was added which involved the recruitment of 1,000 young gay men. All were recruited from general practices in central Vancouver.

The research involves regular visits with subjects who are asked to complete a self-administered questionnaire gathering information on their activities and sexual and health practices including risk behaviours and treatments, a physical examination and blood samples from which immunologic and HI antibody testing is done.

The VLAS findings have had important impacts on researchers' understanding of the incidence and risk factors associated with the disease, as well as its clinical progression and natural history. The study has also informed public policy. Examples of impacts and effects include: identification of risk factors related to HIV/AIDS which can be used in education campaigns (e.g., such as sexual practices, use of alcohol/drugs); tracking of those practices or characteristics which seem to delay or inhibit the progression of the disease; using the data to develop "back calculation" methods to better estimate HIV prevalence in the Canadian population; development of a system of "staging" of the disease and tracking of the effect of new treatments.

LESSONS LEARNED CASE STUDY No. 3:

Vaccine Development Research Program

In 1994, the Vaccine Development Research Program at the National Laboratory for HIV Pathogenesis became part of NAS-II. The goal of this research, to develop an HIV/AIDS vaccine, takes into consideration that worldwide, most individuals now being diagnosed with HIV cannot afford antiretroviral therapy or would not be able to reliably comply with such a demanding treatment regimen. This program is an example of the internal research supported by NAS-II in pursuit of its third goal, to develop effective drugs, therapies and vaccines.

The research program uses the simian immunodeficiency virus (SIV) in Macaque monkeys to evaluate the effectiveness of the attenuated vaccine approach to HIV/AIDS vaccine development. SIV is genetically related to HIV-2, and simulates very closely HIV in humans. Monkeys are injected with the attenuated (killed) vaccine, attempts are made to infect them with the virus, and their immunity is evaluated.

The attenuated vaccine approach is considered by the World Health Organization be a promising approach to HIV/AIDS vaccine development, but commercial organizations have stayed away from this it because of the potential that the virus will revert to a more virulent form. The challenge of this research program is to develop a vaccine which will be completely safe.

In this research program, collaborations have been undertaken with a number of academic, commercial and government organizations, including McGill University, Institut de recherches cliniques de Montréal, NIBSC United Kingdom, Karolinska Institute Sweden, Paul Ehrlich Institute Germany and NIH United States. These collaborations have helped to unify understanding of the effectiveness of this approach to HIV/AIDS vaccine development. Research results have also been presented at several national and international conferences and published in peer-reviewed journals.

On the subject of the contribution of NHRDP/MRC's joint programs to the development of vaccines, drugs or therapies, a majority of respondents were of the view that the joint programs have had little or no impact on the generation of new knowledge (i.e., 52 per cent indicating a one, two or a three on a five-point scale). Respondents held similar views regarding the effectiveness of MRC's programs in generating knowledge relevant to both education and prevention services, as well as care, treatment and support services. In both these areas, a majority of respondents (i.e., 60 per cent and 63 per cent indicating a one, two or a three on a five-point scale, respectively) were of the view that the MRC's programs were only marginally effective in generating new knowledge.

Lastly, respondents were asked about the extent to which both the NHRDP's and the MRC's Career and Training Awards had increased Canadian capacity for HIV/AIDS research. Two-thirds of respondents felt that the NHRDP's Awards had significantly increased Canadian capacity for HIV/AIDS research (i.e., 68 per cent indicating a three, four or a five on a five-point scale), whereas one-quarter of respondents felt that the MRC Career and Training Awards had achieved the same result (i.e., 27 per cent).

Thirty-eight per cent of respondents to the survey of people living with HIV/AIDS felt that research has helped people living with HIV/AIDS a lot with 17 per cent stating it has helped very much. Thirty-six per cent felt it has helped somewhat. Only eight per cent felt that research has helped not at all or almost not at all.

4.4 Effectiveness of Strategy Components

(a) Health Protection Branch

The AIDS epidemiological and surveillance information produced by HPB is generally considered to be of exceptional quality and utility, although respondents would like to see more done with respect to HIV surveillance. This information is disseminated broadly, through regular publications (Quarterly Surveillance Reports, Epi Updates).

In particular, representatives of provincial/territorial governments reported a high level of satisfaction with the epidemiological activities of the LCDC. The data collected by LCDC is particularly important to smaller provinces/territories, which do not conduct any data analysis on their own. All respondents agreed that the national and provincial/territorial information LCDC provides is extremely useful. Respondents reported that where the data are already being collected by the province/territory, LCDC provides a national picture and comparisons with other provinces/territories. The data are being used to establish research priorities, to target risk groups and develop programming. Respondents also agreed that the LCDC has provided leadership in this area. Very few provinces/territories reported having made use of LCDC's Targeted HIV Cluster Investigations.

Canada has a strong international reputation in terms of comprehensive and reliable AIDS surveillance tracking and analysis. One area of concern mentioned was the lack of AIDS incidence information in the Aboriginal population. Some suggestions made by regional Health Canada representatives included: need for more user friendly format (currently considered to be too "scientific"), more frequent, and more readily accessible written publications, as opposed to oral presentations.

The Branch has come under some criticism for failing to develop reliable surveillance of HIV infections. (HIV infection rates are considered to be key to planning prevention and care activities). However, while AIDS is a reportable (legally required) disease, in three provinces, accounting for over half of AIDS cases (British Columbia, Alberta and Quebec), HIV is not, making it more complex and costly for collecting and tracking adequate national HIV data. It should be noted that the issue of collecting information on HIV infections has raised issues in other countries around balancing information needs to support public health strategies and the human rights of patients. LCDC has made significant progress toward national tracking of HIV. Work toward an HIV database is nearing completion, though high quality data will not be available for approximately 24 months.

The Drugs Directorate was generally commended for its work on drug approvals. Timeliness and responsiveness of approvals has improved over the past several years, with over 20 submissions having been approved in the last two years, though representatives in the HIV/AIDS community would like to see continued improvements in this area. The laboratory activities at LCDC involving quality assurance of laboratories and reference testing was also recognized as both important and satisfactory in terms of its implementation. The regulation and approval of test kits for blood screening and the regulation of the blood transfusion system are also perceived to be effective.

Although few provincial/territorial representatives felt knowledgeable enough to answer questions concerning the laboratory activities of the LCDC, those who responded had a high level of satisfaction.

There is some question within the research community about the role and appropriateness of intra-mural research conducted by HPB, as it is believed that this research is not submitted to a strict peer review process as is the case in grant-based extra-mural research.

(b) Health Promotion and Programs Branch

Community Action

The *AIDS Community Action Program (ACAP)* is generally viewed as one of the key successes of the Strategy. Community-based programming is perceived to be very effective in terms of reaching many of the populations which have been affected by HIV/AIDS (see Table 4.3). The program is credited with building an infrastructure at the community level to address needs and to give a voice to the HIV/AIDS community. Compared to the national AIDS programs of other countries analyzed in the international comparative case studies, Canada's partnership with community-based organizations — regarded as a key success factor in national programs — compares favourably. In 1995/96, 320 partnerships were created by funded community-based groups and the services of 6,965 active volunteers (translating into 399,440 volunteer hours) were utilized. The network of community-based programs has also been instrumental in introducing "forward looking" programs which address emerging issues observed by those "on the ground". Examples of projects that have been undertaken are presented in Table 4.4.

TABLE 4.3
Number of ACAP Projects by Target Population

Target Population	Total Number of Projects 1995/96	Total Amount of Funding 1993 to 1998
Persons Living with HIV/AIDS	34	$5,226,989
Volunteer (development, training, etc.)	24	2,469,540
Women	19	1,931,564
Youth	16	1,592,197
Aboriginal	14	1,543,939
Immigrant/Visible Minority	14	1,127,396
Resource Centres	5	231,504
Community Development	5	1,350,409
Men Who Have Sex With Men	4	561,500
Injection Drug Users	3	118,277
General Population	3	429,680
Gays/Lesbians in general	2	654,087
Multiple Target Groups	43	5,728,299
Other	43	5,623,990
TOTAL	229	28,629,371

Source: AIDS Community Action Program, 1996.

TABLE 4.4
Examples of National and Regional Projects Funded Through ACAP 1993 to 1997

Project Title	Description
Prevention Education	
HIV/AIDS Prevention for Newcomers	This project worked in partnership with settlement organizations and ASOs in Atlantic Canada to develop a culturally and linguistically sensitive AIDS prevention program for immigrants. It established a resource bank of ethnocultural AIDS resource material from across the country and designed and implemented a peer education program.
Social Communication Campaign	A multi-media campaign aimed primarily at men who have sex with other men and who live, come to or work in downtown Montreal. Its general aim is the creation of an environment conducive to the adoption and maintenance of a healthy and safe sex life. Partnerships developed with business have led to price reductions and increases in the number of locations.
HIV/AIDS Outreach Project	The goals of this project are to provide community-based, culturally appropriate awareness and promotion programs on HIV and AIDS with special focus on youth and hard-to-reach adults and to develop a supportive environment for HIV+ individuals and their families. It operates a centrally-located drop in centre and a resource library, as well as a soup kitchen. Partnerships have been developed with non-health related government and business agencies.
Strengthening Organizations	
Volunteers Management Manual	The aim of this project was to provide effective guidance for volunteers. A volunteer resources management manual was developed. This project involved community AIDS organizations, organizations which specialize in the management of volunteers and volunteers.
AIDS Shelter Project	This is an operationally funded project which supports the ongoing work of the AIDS Shelter Coalition of Manitoba (ASCM) to provide better access to housing, income security and support services for PHAs (particularly nutrition needs).
Community Projects	The purpose of this project was to stimulate rural outreach initiatives in the province of New Brunswick. Using a community development model, this project helped three isolated regions in the province develop education and support programs that can be maintained by volunteers and interested partners

Project Title	Description
Reducing Barriers	
Empower '94 (Ontario)	The objective of this project was to encourage isolated People with HIV/AIDS to become involved with the greater Ontario HIV/AIDS community; to identify health promotion issues not currently being well addressed; to identify issues and needs that would assist HIV/AIDS service organizations in their service delivery activities.
2-Spirits Mino-B'Maadziwin Project	The objective of this project is to address the identified issues of homophobia, racism, poverty, fear and stigma associated with HIV/AIDS for 2-spirited PHAs both within Aboriginal communities in Ontario, as well as the community at large. Workshops dealing with these issues were conducted in an effort to reduce barriers for members of the Aboriginal population infected and affected by HIV/AIDS.
Bridging the Gap: Community/Medical HIV/AIDS Advocacy	With the support of the Victoria Medical Society, this project aimed to improve the quality of care for persons living with HIV/AIDS by working with local physicians and other health care providers by way of a needs assessment, consultations, roundtables, workshops and training sessions.

In terms of target groups, ACAP projects are difficult to characterize, as the majority have had multiple targets (i.e., could include IDUs, Aboriginal people, youth) and many have focussed on capacity development (e.g., through volunteers or community development). We note, however, that projects aimed specifically at Aboriginal groups and injection drug users — two populations of current concern — received 5.4 per cent and 0.4 per cent of project funds, respectively. It should also be noted that the category "multiple target groups" may also include these populations.

Provincial respondents were very supportive of the ACAP program, and enthusiastic about the effectiveness of this program. Representatives of provincial/territorial non-governmental organizations were particularly enthusiastic when speaking of the ACAP program. For example, one NGO representative described ACAP as their best partnership, stating that program representatives are "true friends" who have provided strong support. ACAP is credited with supporting programs that no one else would, and with helping to reach more people from high-risk populations.

All provincial respondents agreed that ACAP has created an adequate infrastructure of effective community-based organizations. However, respondents stated that the infrastructure is not sustainable. For many organizations ACAP is their most important source of funding; it was felt that only some organizations also receive a significant amount of support from their provincial/territorial government. Many respondents indicated that if ACAP were to end, the impact would be drastic, with many organizations disappearing. It was felt that ACAP should do more to help and/or encourage organizations to diversify their base of support. The panel study of stakeholders showed that the proportion of organizations receiving their primary funding from the federal government did not change significantly from Wave 1 (47 out of 94 panellists) to Wave 2 (40 out of 94 panellists).

National meetings are held with ACAP program consultants on a regular basis. During these meetings, regional and national updates of the regions are provided and action to be taken is decided on. Other issues, such as strategic directions with the Care, Treatment and Support Program and sustainability workshops, are also discussed. One of the commitments under NAS-II is the evaluation of programs and projects, focussing on: the facilitation of community and NGO action; model and resource development and evaluation; and NGO infrastructure core funding.

Education and Prevention

The *AIDS Education and Prevention Unit* provides operational funding to three national partners, the National AIDS Clearinghouse and CSC, as well as funding community-based research, the development of targeted behavioural and societal change risk reduction programs and national awareness campaigns (see Table 4.5). The decline in the spread of HIV up to 1991 provides some indication of success of education and prevention activities prior to NAS-II. The spread of the disease into different populations will require a more targeted approach in future. Examples of projects undertaken by the AIDS Education and Prevention Unit are presented in Table 4.6.

Provincial respondents familiar with the Education and Prevention Activities of Health Canada were somewhat less enthusiastic and supportive than they were of ACAP. Many provincial/territorial representatives indicated that they do not use the materials developed by Health Canada, but rather produce their own. Others report adapting Health Canada materials to meet their own needs, stating that national materials are not necessarily well suited to different contexts and regions. For example, two respondents suggested that some materials produced by Health Canada (e.g., "Weighing the Risk", targeted to young women) are appropriate in an urban context, but not in a rural context where values are different. From the responses received, it would appear that Health Canada materials are not widely used in many provinces/territories.

TABLE 4.5
Number of AEPU Projects by Target Population
1993/94 to 1997/98* (NAS-II)

Main Target Population	Total Number of Projects
Youth	17
General Public	12
Injection Drug Users/Drug and Alcohol Abusers	16
Men Who Have Sex With Men	12
Persons Living with HIV/AIDS	6
Street-Involved People	3
Women	12
Legal/Ethical Issues	6
Aboriginal	4
Immigrant/Visible Minority	2
Multiple Target Groups	10
Other	16
TOTAL	116

* Total projects from 1993/94 to June, 1997 inclusive.

Source: Information provided by the AIDS Education and Prevention Unit.

TABLE 4.6
Examples of Projects Funded Through AEPU
1993/94 to 1997/98

Project Title	Description
Prevention and Behaviourial Research	
Community HIV Prevention Project: Phase II — An Exploration of the Determinants of Sexual Behaviour Among Youth at Risk for Heterosexual Transmission of HIV	This project consists of an innovative study of the determinants of risk behaviour among 9-18 year olds in Eastern Newfoundland. It provides an opportunity to explore risk determinants in an isolated area with a documented heterosexual outbreak of HIV.
Qualitative Determinants of Risk Behaviour — 8 Studies	This network of innovative two year community-based studies focuses on disadvantaged women and men who have sex with men. They will explore the interaction of multiple risk factors like poverty, alcohol and other drug use, social marginalization and power imbalances in relationships.
Synthesis of Information and Knowledge Development	
Northern Aboriginal Version of "Skills for Healthy Relationships"	The Northwest Territories Association for School Health developed an Aboriginal adaptation to the comprehensive sexuality and HIV prevention program "Skills for Healthy Relationships".
Working Together on HIV/AIDS Prevention Among Street Involved People	The Working Together-Edmonton Coalition refined, documented and shared models and tools with other groups by developing and disseminating a document, and delivered a workshop on agency collaboration and client group participation in HIV/AIDS prevention among street-involved people.
Health Promotion in Action Phase II	The purpose of this project is to establish a national capacity of community health promotion as it affects the continuum of HIV prevention activities.
Experimental Development Programming (Demonstration)	
Youth Awareness Video: A Time for Mercy	This video, which personalizes issues of HIV and AIDS for youth and young adult audiences, was developed with the assistance of corporate sponsors.
Condom and Pill Project — Planning and Evaluation, Phase I	This is a physician based intervention that is intended to promote dual protection; use of a condom along with birth control pills, as a means of reducing sexually transmitted diseases and the transmission of HIV/AIDS.
Intramuscular Steroid Use Program	The purpose of this contribution was to undertake a leading edge project to support change in youth's high risk behaviour associated with needle sharing in injection steroid users, by building an existing grass-roots organization activities in the area of injection-drug-use harm reduction.

Source: Information provided by the AIDS Education and Prevention Unit.

Care, Treatment and Support

AIDS Care, Treatment and Support Unit is generally seen to have been effective in developing care and support models for HIV/AIDS patients. The program has focused on training health professionals and community-based organizations in care, treatment and support of people living with HIV/AIDS. A series of comprehensive care modules has been developed and disseminated. It has also provided funding for the Canadian HIV Clinical Trials Network and the AIDS Treatment Information Network. The patient care models and fostering of individual empowerment around treatment have had applicability beyond HIV/AIDS to other diseases such as breast cancer. Examples of projects undertaken by this unit are presented in Table 4.7. Case Study No. 4, presented on page 72, describes Project Accès in Montréal, a pilot project in the area of care, treatment and support.

The funding to professional organizations (Canadian Medical Association, Canadian Nurses Association) provided by the Care, Treatment and Support program was an area identified by key informants as a candidate for withdrawal or at least reduction in federal effort. However, as noted previously, professional associations questioned in the stakeholder surveys do not necessarily feel that their capacities have been enhanced. Health professionals are perceived by key informants to have now received adequate information/training which they may have required during the initial stages of the epidemic. As well, it is believed that these organizations should be responsible for and capable of future upgrading.

TABLE 4.7
Examples of Projects Funded by the Care, Treatment and Support Program 1993-94 to 1997-98 (NAS-II)

Project Title	Description
Support for Professional and Non-professional Education and Training	
Living with HIV/AIDS and Dementia	The objective of this program was to increase the knowledge and involvement of the Canadian Psychiatric Association members in HIV/AIDS issues.
Consensus Workshop on TB/HIV	The goal of this project was to support a national consensus workshop on the dual infection of HIV and TB for provincial HIV coordinators, provincial TB control officers and representatives from the partners in the National AIDS Strategy.
Beyond Grief: Dealing with Losses Associated with HIV/AIDS	The purpose of this project was to provide people in Newfoundland with an opportunity to understand and deal with the losses which are mounting in their province as a result of HIV/AIDS.
Psychosocial/Quality of Life Support and Research	
Nutrition and Home Support AIDS Training	The purpose of this project was to integrate information about nutrition into the 1990 home support AIDS training package.
Workshop: "The Case of a Terminal AIDS Patient and the Hospice Staff"	This workshop dealt with the psychosocial impact of HIV/AIDS on families and caregivers.
HIV/AIDS Survival Training Program	The purpose of this project was to conduct a study of alcohol and substance abuse in the HIV+ community in order to determine methods of reducing high risk behaviours and increasing safer sex practices.
Model Demonstration and Evaluation	
Caring Together: Integrated Model of Community Care	This demonstration model developed, implemented and evaluated a model of integrated care for persons with HIV and AIDS, their families and caregivers, in the Edmonton region.
Asian Volunteer Training and Coordination Modules	This project provided volunteers working in the area of HIV/AIDS in the Asian community with knowledge and skill-building activities. Integrated within it is a culturally designed volunteer training and coordination module.
Collaborative Model in HIV/AIDS Practice	This joint project between the Canadian Nurses Association and the Canadian Medical Association undertook a literature search on models of multidisciplinary collaborative practices in order to develop a background paper called "Working Together: A Joint Canadian Nurses Association / Canadian Medical Association Collaborative Practice Project, HIV/AIDS Example".

Source: Information provided by the Care, Treatment and Support Program.

LESSONS LEARNED CASE STUDY No. 4:

Projet Accès, Montréal

In large metropolitan areas such as Montreal, there are many public and non-government structures involved in treatment, care and support of people living with HIV/AIDS. Their effectiveness can be limited by poor coordination and communication, causing unnecessary inefficiencies and problems for clients. With funding and support from NAS-II, the Centre québécois de coordination sur le sida (CQCS) designed a new intervention model, Project Accès, to overcome these difficulties for people living with HIV/AIDS in the central Montreal area. (A similar project was also conducted in Edmonton.) This project demonstrates the Strategy's efforts to develop improved care and treatment models for people living with HIV/AIDS.

The objectives of Projet Accès were: to coordinate and integrate the actions of the organizations and groups involved in treatment, care and support for people with HIV/AIDS, (hospitals, CLSC's, and community groups); to provide training to health professionals, especially with regards to palliative care; and to increase the awareness and knowledge of palliative care for people living with HIV and their families and friends.

A coordinating committee comprised of senior management members of Montreal health and community organizations was mandated to identify needs, weaknesses, and resources; implement new services; identify training needs for professionals; and plan common actions for palliative care. A new individualized self-help approach was developed, workshops and training sessions were organized for professionals, a directory of resources and services was created, and a self-help guide for people living with HIV/AIDS was developed.

The effectiveness of Projet Accès varied from one component to another. A project evaluation showed that the self-help guide and training programs were successful in raising awareness of needs and resources available, and in improving the coordination of the care and treatment services. However, the coordinating committee was mostly effective at finding solutions that could be applied by a specific group or institution, while solutions that involved the coordination of many groups or institutions were less effective. The project resulted in few lasting changes to the system, in part because it was overtaken by the creation of new regional health structures in the health system reform. This project illustrates the difficulty of inter-agency coordination, but points to the importance of training professionals involved with people living with HIV/AIDS.

A minority of provincial respondents were familiar enough with the Care, Treatment and Support activities to discuss them. Those who were familiar with these activities agreed that, during NAS-II, models and resources for care and support have been developed which meet the needs of the province and make a value-added contribution. Compared to programs in other countries, Canada's National AIDS Strategy has been relatively less successful in articulating areas of federal and provincial responsibility for care and treatment for HIV/AIDS across jurisdictions.

Supports Received by People Living with HIV/AIDS

Respondents to the survey of people living with HIV/AIDS were asked about the kinds of support they are receiving, as a means of assessing how well the Strategy is actually providing care, treatment and support to people living with HIV/AIDS. The primary kinds of help being received by respondents were informational (83 per cent), followed by treatment (80 per cent) and moral support (70 per cent). Forty-eight per cent of respondents indicated receiving financial support, with 20 per cent indicating receiving help with living arrangements. Only one per cent of respondents indicated not receiving any help at all. Eleven per cent of respondents indicated receiving other types of help. These other types of help varied widely with no one being cited more than twice. Examples of these include: medical coverage, help with food, self-help and skills training.

Forty per cent of respondents stated they are receiving a lot or very much help in living with HIV/AIDS with just 34 per cent indicating they are receiving some help. At the opposite end of the scale, 17 per cent stated they are receiving "little" help and seven per cent said they are receiving almost no help at all.

When asked what kind of help they need more of, only 13 per cent of respondents need more treatment. In contrast, 45 per cent indicated financial support. Seventeen per cent need more moral support and 12 per cent indicated that they did not need more help.

Based on their experience, respondents tended to feel that the services in their region for people living with HIV/AIDS were somewhat organized (37 per cent) to quite organized (36 per cent). Seventeen per cent were of the opinion that the services in their region are very well organized. At the other end of the spectrum, only four per cent feel that services in their region are not at all organized.

Conclusions: Health Promotion and Programs Branch

There was broad agreement among respondents that the programs and activities which have been funded by HPPB have been crucial in terms of preventing the spread of HIV/AIDS and in improving treatment options and care and support. There is little disagreement that community-based programming is highly effective, particulary in reaching marginalized or targeted populations, and is also cost-effective in its reliance on community organizations and volunteers. However, as mentioned previously, this was also the area in which the validity of the federal role was questioned. The need for some provinces to assume their financial responsibility with respect to providing health services to the HIV/AIDS population was raised, as well as the possibility that provinces may be in a better position to understand and respond to the needs of their local communities. However, doubt was expressed that all provinces would be capable of undertaking this funding. While it is probable with reduced federal involvement, patients would continue to receive treatment and care, it is believed that provinces would not continue to develop or adapt education and prevention programs.

(c) Medical Services Branch

There was a high degree of consensus among key informants at all levels that the issue of HIV/AIDS in the Aboriginal population has been a weakness in the Strategy. There is little detailed knowledge available about the prevalence and incidence of HIV/AIDS among Aboriginal people. Nevertheless, there is a consensus that this situation will become more serious over time. Research into dosing and treatment strategies among Aboriginal people is similarly limited. Case Study No. 5 (on page 75) on the Fourth Canadian Aboriginal Conference on HIV/AIDS and Related Issues illustrates how the Strategy has contributed to raising awareness on the issue of HIV/AIDS in the Aboriginal population.

LESSONS LEARNED CASE STUDY No. 5:

Fourth Canadian Aboriginal Conference on HIV/AIDS and Related Issues

The Fourth Canadian Aboriginal Conference on HIV/AIDS and Related Issues was held from November 9 to 13, 1996, in Halifax, Nova Scotia. The conference was hosted by Atlantic First Nations AIDS Task Force headquartered in Halifax. The conference is an example of awareness and mobilization efforts being supported in Canadian aboriginal communities as part of NAS-II.

The theme of this conference was "Healing Our Nations". This theme was chosen to reflect the tremendous healing power found in the cultural and traditional ways of Aboriginal People and reflects the work and efforts being made by the Aboriginal community regarding HIV/AIDS.

The overall goal of the conference was to give Aboriginal people living with HIV/AIDS an opportunity to voice their needs, concerns and experiences. At final count, there were 360 registered delegates. Almost half of these (132) received full or partial sponsorship to attend. The conference lasted three days and included 35 workshops centred around five "streams": research and surveillance (6 workshops); psycho-social issues (11 workshops); education, prevention and outreach (10 workshops); community/organizational development (6 workshops); and treatment information (2 workshops). In addition to opening and closing addresses, there was a panel of five Native individuals living with HIV/AIDS who spoke to the conference attenders about their lives.

This conference marked the second time that a community based organization planned and hosted a national Aboriginal AIDS conference. (The first conferences were closely affiliated with academia.) At this conference, more than half of the presenters were Aboriginal and therefore was a better reflection of the increase in expertise being developed in Aboriginal communities.

Overall, the conference was considered to be a success. One of the major impacts of the conference was to provide hope to those living with HIV/AIDS that something is being done. As well, a great deal of information was imparted at the conference. The testimonial component of the conference (by PHAs) contributed to the emotional impacts.

The strengths of the conference were the use of ceremony and song to bring the different cultural groups and bands together (representatives from over 50 tribes were present) as they serve as the common bond between them. The role of elders and ceremonial people was very strong and was considered to have been key to the success of the conference.

It is believed that HIV testing is generally accessible to Aboriginal people on-reserve, largely through community health stations. All community nurses have received training in pre- and post-test counselling. Although HIV testing is not necessarily advertised in communities, it has been encouraged through education and prevention activities. However, as previously mentioned, awareness of the use of testing services appears to be low among Aboriginal groups surveyed in the stakeholder surveys.

Much of MSB's activities have been focused on education and prevention. For example, community programs have been developed with certain First Nations and Inuit communities. As well, local program and service deliverers have been trained in culturally-appropriate education, prevention, care and treatment services. Although respondents acknowledged that there is still work to be done, given the level of funding, prevention and education activities have been effective in increasing knowledge and awareness of HIV/AIDS.

Specialized treatment for HIV/AIDS is currently only offered off-reserve. As the number of AIDS cases grows, the ability to improve support on-reserve for people wishing to return to their reserves will have to be addressed. As an aside from the Strategy, given the movement towards devolving responsibilities to the reserves, the cost to communities to deal with full blown AIDS cases requires consideration and should be factored into the transfers.

The efforts of MSB and the Strategy in dealing with this issue have been hampered by a number of factors. Poverty and ill health are typical features of on-reserve Aboriginal communities. Interrelated issues such as sexual health, substance abuse, poverty, discrimination and inaccessibility to other services work to complicate the efforts around HIV/AIDS. Other factors include:

- ☐ ***Lack of funding.*** There is a consensus that MSB is underresourced with respect to the difficulty and suspected seriousness of the problem. Funding to MSB accounts for roughly six per cent of NAS-II budget; given the suspected state of the epidemic in the Aboriginal community, this appears, to some, to be somewhat inequitable. Further, the distribution of funding (from the federal government to provincial government to region and then to the Band Council) often leaves few dollars for Councils to undertake any far-reaching or innovative programs specifically directed toward HIV/AIDS.

- ☐ ***Jurisdictional issues.*** There are jurisdictional issues apparent in the Strategy itself which may pose barriers to the continuity of services and care. ACAP funds programs and activities directed toward off-reserve Aboriginal people, while MSB funds programs and activities for on-reserve Aboriginal people. In reality, however, individuals frequently move on- and off-reserve. As well, efforts have not typically been made to link Aboriginal NGO's with the provinces (or other national NGO's for that matter) due, largely, to the perception that Aboriginal issues are solely a federal responsibility.
- ☐ ***Resistance from the community itself.*** There has been a reluctance on the part of Aboriginal leaders to draw attention to the issue of HIV/AIDS in their community. This has been partly due to cultural taboos and myths. Although great strides have been made to dispel myths about HIV/AIDS (e.g., it is a homosexual disease), misinformation persists. A further challenge in engaging discussion on prevention issues is a reluctance on the part of Aboriginal people to openly discuss the topic of sex. However, it is believed by some that progress is being made in this area.
- ☐ ***Perceived lack of leadership*** with the federal government to deal with Aboriginal health issues.
- ☐ ***Geographic isolation of on-reserve population.*** Aboriginal people on reserve lack access to accurate and private testing, as well as treatment and support options.
- ☐ ***Greater concern among Aboriginal groups with devolution of power.*** HIV/AIDS will continue to be seen as a low priority until new political arrangements are concluded.

(d) Non-Governmental Partner Organizations

Most key informants favour a strong role for national non-governmental organizations in the future. These organizations have close links to their respective communities (e.g., organizations representing the HIV/AIDS community, HIV/AIDS researchers), bringing various perspectives and valuable information and resources to the planning exercise. They are also well-positioned to disseminate information to their respective constituencies.

Some respondents questioned the selection of the five non-governmental organizations which compose the National Partners' Forum. It was suggested that the role of these groups should be reviewed and perhaps a more flexible process adopted. As a way to re-evaluate the role of these groups, the amount of investment and rationale should be incorporated into a renewed strategy.

The Canadian AIDS Society (CAS) and the Canadian Association of HIV Research (CAHR) were favoured by most respondents (though CAS may not be adequately representing all regions, particularly the West) as making an important contribution to NAS-II and having a continued role in a future HIV/AIDS Strategy.

There was a broad consensus among key informants that the Strategy should reconsider the role of the Canadian Hemophilia Society. HIV/AIDS in the hemophiliac population has been a significant issue and the CHS has played an important role. However, the steps that have been taken to ensure the safety of the blood supply are expected to have eliminated this threat. Therefore, the continued role of this group is questionable.

The CPHA has been a disappointment to some federal respondents, largely because of a perceived lack of accountability. While the CPHA was appealing because of its links to public health units across the country, this network has not been fully utilized to communicate treatment and prevention information. However, provincial respondents were more positive about the CPHA's advocacy role and its support of the Clearinghouse.

The role of CANFAR is also questioned. HIV/AIDS research is expensive and CANFAR has not, to date, raised a great deal of funding. There is also a need to evaluate the boundaries between the various national organizations. Competition in fundraising is a problem.

4.5 Key Conclusions

Overall, the National AIDS Strategy, Phase II, has been moderately successful. Although gains have been made in education and awareness, the Strategy has not succeeded in stopping the spread of HIV. Major challenges remain in reaching some difficult populations, including Aboriginal Canadians and injection drug users.

NAS-II has been successful in ensuring the provision of care, treatment and support to people living with HIV/AIDS, through the creation and mobilization of an infrastructure of non-governmental organizations and through development of professional skills. A large proportion of surveyed individuals living with HIV/AIDS state that they are receiving information, treatment and moral support. Recent declines in overall deaths from AIDS are attributed largely to improved treatments, made available in part through NAS-II.,

The research activities of NAS-II have effectively contributed to NAS-II objectives, especially of ensuring effective treatment for people living with HIV/AIDS. The Strategy has been successful in expanding the knowledge base through comprehensive and reliable AIDS surveillance systems.

However, more development is needed in HIV surveillance, especially for vulnerable groups. The regulatory matters, drug approval and blood safety tests handled through NAS-II were also effective components.

CHAPTER

5 COST-EFFECTIVENESS OF THE NATIONAL AIDS STRATEGY

This chapter presents evaluation results pertaining to cost-effectiveness of the Strategy.

(a) Perceived Cost-Effectiveness

The fourth objective of NAS is to implement the components of the Strategy in a cost-effective manner. Virtually all key informants agreed that the funding for NAS-II had been a valid investment for the federal government, as it is believed that the prevention activities of the Strategy avoid the costs of new HIV/AIDS patients. Care, treatment and support activities are seen to avoid or delay institutionalisation of patients, thus reducing hospitalization costs.

The evidence which was most often offered by key informants to support their perceptions was the figures on the estimated lifetime direct treatment costs for a person with HIV/AIDS. The substantial costs (including during therapies and care) means it is relatively easy to be cost-effective: respondents indicated that in order to be cost-effective, three infections must be prevented each day as a result of Strategy expenditures. (This may be now given the greater expense of new combination drug therapies and the fact that AIDS patients are living longer. These figures also only include the direct costs of treating AIDS and do not include the indirect costs such as lost productivity or indirect gains such as re-integration to work). There was a general consensus among key informants that the Strategy had easily accomplished this return.

There are a number of elements which contribute to the cost-effectiveness of NAS-II:

- ☐ Peer review of funded research and community-based projects to ensure relevance and to avoid duplication (e.g., all extramural research funded by MRC and NHRDP is reviewed by a panel of recognized scientific experts), thus avoiding unnecessary duplication and poor or irrelevant research.
- ☐ In some cases, leveraging of costs. For example, the CTN leverages $7.5 million annually in drug costs from pharmaceutical companies for clinical trials. The ACAP leverages a large number of volunteer hours.
- ☐ Efforts to ensure that model development is transferable to other sectors/diseases (for example, palliative care models such as *Living with Dying at Home* have been used for cancer patients).
- ☐ The use of non-governmental and voluntary organizations for the delivery of services.

In terms of whether the funding could have been better spent to achieve greater results for the equivalent investment, key informants were somewhat less certain. Most respondents believed that the investments were appropriate and well-directed; that is, the Strategy did not waste time or efforts pursuing irrelevant or irresponsible activities. Provincial and territorial respondents believed that the Strategy was particularly cost-effective in terms of the extent to which programming was expanded.

To improve cost-effectiveness of a renewed NAS, the following were suggested:

- ☐ A focus on "the hot spots" within the epidemic — targeting specific groups which are experiencing higher than average rates of infection (i.e., Aboriginal people, IDUs). Concentrating efforts on these groups, will also help reduce the rate of infection in the general population occurring through interaction with these groups.

- ☐ Greater contributions from the private sector.
- ☐ Insistence on greater funding responsibility from provinces, particularly from those not making significant contributions in the programming area.
- ☐ Continued scrutiny of all research spending for its priority, pertinence and relevance.

(b) Federal vs. Provincial Expenditures in AIDS Prevention

Table 5.1 shows federal, provincial and municipal expenditures on HIV/AIDS prevention from 1985/86 to 1996/97. These data, provided by the Canadian Policy Research Network, show that the relative federal contribution to total public sector expenditures on HIV/AIDS prevention has declined from 30.4 per cent in 1992/93 to 25 per cent in 1996/97, while there has been a 33 per cent increase in total expenditures over that period. This indicates that other levels of government are assuming increasingly greater shares of expenditures in HIV/AIDS prevention, and may indicate that NAS-II has successfully encouraged provincial delivery of prevention activities over the life of NAS-II.

Case Study No. 6, on page 85, describes Street Connections in Winnipeg, which is an example of a program which is not financed by Health Canada, but is working toward the same prevention goals as embodied in the Strategy.

TABLE 5.1
Federal, Provincial and Municipal Expenditures on HIV/AIDS Prevention, 1985/86 to 1996/97 (in thousands)

	1985/86	1986/87	1987/88	1988/89	1989/90	1990/91	1991/92	1992/93	1993/94	1994/95	1995/96	1996/97
Federal	0	1,932	2,828	12,340	15,798	18,636	17,845	18,402	20,828	20,957	20,234	20,277
Provincial and Municipal	4,912	6,538	19,912	22,404	31,420	32,164	35,623	42,106	46,511	51,522	54,612	60,487
Total Public Sector Expenditures	4,912	8,470	22,741	34,749	47,218	50,801	53,471	60,508	67,319	72,478	74,846	80,765

Source: Unpublished data provided by Terry Albert, Canadian Policy Research Network. Please do not cite without permission. These data include public education, primary prevention and harm reduction activities, but do not include care and treatment costs.

LESSONS LEARNED CASE STUDY No. 6:

Street Connections, Winnipeg

With all of its funding coming from Manitoba Health, Street Connections in downtown Winnipeg is an
of a program working toward the same goals as NAS-II but implemented independently of the Strategy.

Using a "harm reduction model", Street Connection's mission is to facilitate street-involved individuals' change and growth, helping them move toward independence and integration into a healthy community. It provides a variety of health, social and bridging services to street-involved individuals in a non-judgemental manner, and plays an advocacy role through bringing harm reduction into mainstream agencies, such as Family Centres.

Street Connections operates out of two fixed sites: a house which is open to females, their children and transgender clients, and a storefront; and a mobile van. The main activities of Street Connections include: drop-in/resource centres; outreach; needle exchange; health information, services and supplies from two nurses; on-site family and community services; client case management; and counselling and crisis intervention. Its target populations include male and female prostitutes, street youth, solvent users and intravenous drug users. In 1996/97, 64 per cent of the program's contacts were female and 74 per cent were Aboriginal persons. In 1996/97, 262,058 new needles were given out and 259,780 used needles were exchanged.

Barriers to Street Connections' operations have been numerous, and include the conservative climate, a perception that the police and Street Connections are working at cross purposes; and attempts of businesses and residents of the inner city to clean up their neighbourhood.

Street Connections is innovative in that it provides integrated service delivery, including access to mainstream resources; it is the only formally funded needle exchange program in the province of Manitoba; and it provides accessible and non-judgemental services such as nursing care. Changes to how services are delivered are constantly reviewed, but one of the challenges currently faced is the limited resources to allocate over a broad based mandate.

(c) *International Comparisons*

Although direct international comparisons of cost-effectiveness are not advisable given the very different nature of health systems, epidemics and resources across the world, Table 5.2 presents some descriptive information on characteristics of the four countries examined in the international comparative case studies.

TABLE 5.2
Characteristics of Selected Countries and HIV/AIDS Expenditures

	Canada	U.S.A.	Australia	Germany
Population (M) (1991)	26.5	249.2	16.9	77.6
AIDS incidence per 100,000 (1995)	3.4	15.2	2.9	1.5
Estimated HIV infections (1997)	42,500-45,000	650,000-900,000	18,787	50,000-60,000 (1992)
Years federal Strategy introduced	NAS-I: 1990 NAS-II: 1993	1997	1989	1987
Annual federal HIV/AIDS expenditures ($M Cdn)	$42.6 M	$7,457.8M[1] ($US)	$72.3 M[2]	$45.3 M

1. *The National AIDS Strategy* (Appendices), 1997, The White House; 1995 figures; includes federal responsibility for health care to the uninsured.
2. Includes federal transfers to hospitals.

These data show first that the burden of HIV/AIDS in the United States — the first industrialized country to face the epidemic — is by far the greatest. Although the United States has made considerable expenditures in HIV/AIDS since the beginning of the epidemic, its first National Strategy was announced only earlier this year. Canada's federal response was implemented somewhat later than that in many other countries, including Australia and Germany. Canada's per capita federal expenditure is situated in between those of Germany and Australia, although direct comparisons are difficult because these countries finance their health care and treatment systems differently.

CHAPTER

6 NATIONAL AIDS STRATEGY MEGA-PROJECTS

This chapter presents summaries of the evaluations conducted of the three NAS-II mega-projects: the HIV Clinical Trials Network, the CPHA National AIDS Clearinghouse, and the HIV/AIDS Treatment Information Network. Data from several sources were used in these evaluations: from case studies of the projects, from the internal review and provincial survey and inventory, and from the stakeholder surveys. In the description of the results for each mega-project, the information provided by key informants attached to the projects is presented first, followed by input from sources external to the organizations.

6.1 Clinical Trials Network

(a) Case Study Results

Continued Relevance

It is in the opinion of key informants involved directly with the Canadian HIV Clinical Trials Network (CTN) that the clinical trials facilitated by the CTN have contributed to the broader Canadian and international research effort to develop new treatment therapies. These trials and other research have contributed to the development of effective new drugs (e.g., 3TC, protease inhibitors) and continue to test the efficacy and toxicity of new combination therapies.

Despite the recent success of new drug therapies, key informants strongly believe that the CTN has a continuing role to play in the development of drug therapies. This is because:

- ☐ While protease inhibitors and combination therapies have been successful in reducing the amount of detectable HIV in the blood, the effectiveness of these drugs in the longer-term is unknown. Past treatment approaches have shown that drug effectiveness can wane over time as the virus becomes resistant. Therefore, continued development of new drug therapies is necessary to eradicate the disease.
- ☐ There is a need for greater attention to management studies related to existing drug therapies — such as refinements to required dosage strength, combination effects and frequency of medication. As the disease moves into more marginalized populations, methods must be found to administer drugs in a more simplified way.
- ☐ There is a need for government-sponsored funding for HIV/AIDS research. HIV/AIDS is not considered to be mainstream research with access to private and public research resources. Continued support for organizations, such as the CTN, maintains high quality research in Canada that would not have access to finding through other sources.

Effectiveness/Success

The key impacts of the CTN, as noted by key informants, include the following:

- ☐ increased the initiation of clinical trials in Canada. While it is difficult to establish with certainty the number of clinical trials that would have been conducted in Canada without the CTN, key informants believe the organization had made a significant positive impact. By providing pharmaceutical companies with access to a variety of CTN services (e.g., scientific review, community review) and access to an established infrastructure of investigators and patients, the CTN is able to attract a greater number of trials to Canada. The CTN received 104 submissions for clinical trials and has accepted 70. The number of participants[18] ever enroled in CTN-affiliated trials is just over 6,000.

- participation in clinical trials has allowed HIV/AIDS patients access to new drug therapies. These drugs have reduced morbidity and mortality and improved the quality of life of HIV/AIDS patients.

- through negotiations with pharmaceutical companies, the CTN has encouraged the conduct of clinical trials in smaller and remote centres in all regions (in all, over 30 centres have participated in CTN-affiliated trials). According to key informants, in the absence of the CTN, clinical trials in Canada would be concentrated in the larger centres of Vancouver, Toronto and Montreal.

- by attracting greater investments in clinical trials in Canada, the CTN has contributed to the development of a cadre of skilled and recognized HIV clinical trialists across Canada. These physicians gain an early familiarity with HIV/AIDS drug therapies and their side effects and are able to provide better care and treatment for their patients. Funding of three Associateships each year encourages new investigators to enter and be trained in HIV clinical trials.

- international collaboration and contribution. CTN literature indicates that 46 per cent of network-affiliated trials have involved international collaboration. Research that has been facilitated by the CTN has resulted in numerous publications and conference presentations in Canada and abroad.

- information dissemination. The CTN has made efforts to ensure broader knowledge and understanding of the results of clinical trials. The CTN distributes information through regular workshops, the CTN website, bi-monthly newsletters, clinical trials information kits for physicians and regular mailings. The CTN also provides trial result information to CATIE which is made available to the HIV/AIDS community and health professionals through the AIDS Treatment Information Network.

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[18] Note that "participants" do not represent individuals. HIV/AIDS patients may participate in more than one trial. For reasons of confidentiality the CTN cannot determine the actual number of persons with HIV/AIDS that have been involved in trials.

Cost-Effectiveness

Evidence on the cost-effectiveness of CTN is derived primarily from two sources: multiplier effects or leveraging of funds from third party sources; and efficiency comparisons with a similar clinical trials network in the United States. In terms of multiplier effects, the CTN figures show leveraging of six times the annual $2.9 million in federal funding. The bulk of this is from pharmaceutical companies ($11 million for drug costs and trial operating expenses) and from provinces for lab tests, office space and salaries ($3.5 million).

In terms of comparative efficiency, evidence gathered by the CTN indicates that the organization is about ten times more efficient than their counterpart in the United States. While the CTN spent the equivalent of one per cent of the budget of the U.S. Clinical Trials Network over a six year period, it enroled about ten per cent of the number of volunteers. Some of the efficiencies are accounted for in terms of differences between the Canadian and American health care systems — the Canadian system being more efficient and some of the costs of the CTN for investigator salaries and overhead being absorbed under general health care budgets. While it is difficult to do a strict comparison, at least half of the demonstrated efficiency could be attributed to the CTN according to key informants.

Coordination of CTN Activities with Other NAS-II Components

Key informants noted that the CTN has an effective relationship with the AIDS Care, Treatment and Support Program which provides funding for the CTN. Coordination between the CTN and CATIE is also perceived to be effective. There is a perception, however, that the Strategy overall is not well-coordinated and the CTN would like to see the national mega-projects more fully involved in planning aspects of the Strategy.

Project Specific Issues

One of the issues which the CTN has raised in this study and in its representations to Health Canada is the limited mandate and lack of funding for the CTN to develop and conduct its own clinical trials. Currently, the CTN may only facilitate clinical trials, with funding of these trials being absorbed primarily by industry. According to CTN key informants, expanding their capacity to conduct clinical trials autonomously would free the CTN from the research agenda that is now driven by pharmaceutical companies. This research has, to date, been focused on testing the efficacy of new drug therapies developed by industry. There are, however, many potentially fruitful lines of inquiry which do not capture the interest of the industry. These include, for example, management studies which focus on testing dosages and on testing drug management. It is also difficult to attract funding for clinical trials of alternative non-pharmacological therapies (e.g., vitamin). The CTN points out that there are precedents for network-funded research like this in the United States.

A second issue is the difficulty of the CTN in planning clinical trials based on the five-year funding horizon. Clinical trials are expensive and are often conducted over a long time period (e.g., two to three years). According to key informants, the five-year funding period severely limits the ability of the CTN to plan and facilitate clinical trials.

Finally, a third issue is the funding of the CTN. The CTN has been asked by Health Canada to search for other sources of funding to supplement the contributions of the federal government. In response, CTN Services was formed which is intended to offer services on a contract basis to pharmaceutical companies. This effort is in the beginning stages only, with a business plan and market situation analysis having been prepared. Key informants from the CTN expressed some doubt about the ultimate success of these efforts, however, to make a substantial contribution to the overall cost of the CTN infrastructure.

(b) *Views of the CTN from Other Stakeholders*

Internal Review Results

According to internal review respondents, the key impacts of the CTN include: increased the number of clinical trials conducted in Canada and thus improved Canadians' access to new drugs; and encouraged more equitable access to clinical trials and new drugs in smaller and more remote centres. Some doubts were raised around the perceived high cost of operating the CTN. As well, there are region-based tensions in terms of the operation of CTN-affiliated trials.

Provincial Survey and Inventory Results

According to respondents in the provincial survey and inventory familiar with it, the Clinical Trials Network has been effective and useful for some provinces/ territories, but has been irrelevant for others. In smaller provinces with few cases, there are few clinical trials and provinces have not really benefitted from the network. However, although the Clinical Trials Network is less relevant to some provinces/ territories, most respondents generally supported the Network and felt that there is a continued role, although some would like to see their activities expanded. Access to the Network was described as "unfair" and felt that it only benefitted a small group of people, mostly in B.C..

Stakeholder Survey Results

About half of the stakeholders (i.e., community organizations and professional associations) who responded to the telephone survey of stakeholder organizations (48 per cent) reported having needed information about clinical trials of new HIV/AIDS treatment. This was significantly higher for community organizations (63 per cent) compared to professional associations (12 per cent).

Of those organizations that needed clinical trials information, many acquired this information directly from the Canadian HIV Clinical Trials Network (44 per cent). About one-third (32 per cent) received this information through their physician or health worker.

The majority of stakeholder groups (70 per cent) were aware of the Clinical Trials Network. Of those organizations that stated that they were aware of the CTN, most (62 per cent) stated that their organization or its clients had needed services like those provided by CTN. This was significantly higher among community organizations (70 per cent) compared to 38 per cent of professional associations. Seventy-three per cent of organizations who needed services like those provided by the CTN have had or currently have clients participating in CTN-affiliated clinical trials. Clients had participated in a number of trials; stakeholders reported a total of four (researchers) to 14 (community-based organizations) trials on average. Only one professional association reported clients participating in clinical trials.

When asked about the extent to which clinical trials were addressing the areas of greatest need, about one-quarter of respondents (28 per cent) did not know. Representatives from professional associations were particularly uncertain, with 50 per cent responding "don't know" to this question. Forty-three per cent of stakeholder organizations felt clinical trials were addressing needs to a great extent (rated four or five on a five-point scale), 18 per cent responded moderately (three on a five-point scale) and 11 per cent, not a great extent (one or two on a five-point scale).

Sixty-two per cent of the stakeholder groups who responded to the survey believed clinical trials had produced benefits for people living with HIV/AIDS. Three per cent believed clinical trials had not produced any benefits and 23 per cent rated the benefit as moderate; an additional 12 per cent did not know.

Satisfaction with the CTN among stakeholder organizations is quite high. Forty-two per cent of respondents reported being satisfied with the activities of the CTN, one in four were moderately satisfied, and 11 per cent were not satisfied.

(c) Conclusion

Overall, the Clinical Trials Network is seen to be a positive feature of the National AIDS Strategy, having improved the capacity to attract and support clinical trials and to distribute access of HIV/AIDS patients to the trials more equitably across the country. However, the survey of persons living with HIV/AIDS indicates that there is considerable demand for clinical trials that is not being met by the current level of clinical trial activity in Canada.

6.2 National AIDS Clearinghouse

(a) *Case Study Results*

Continued Relevance

According to key informants directly involved in the Clearinghouse, it is a unique and extensive source for AIDS education and prevention materials, providing educators in Canada and the world with access to the resources they need through "one-stop shopping". Through its partners, conferences, access to research and requests for information, key informants indicated that the Clearinghouse is kept abreast of ever changing needs which enables them to identify gaps in the information currently available.

The demand for resources has continued to grow along with the size of both the distribution and reference collections, indicating that there is a continuing need for services of the Clearinghouse (see Table 6.1). While its two main clients are, and always have been, AIDS service organizations and the public health community, its client base has broadened and now includes groups such as schools, women's groups, Aboriginal groups and ethno-cultural groups. It is the opinion of key informants that, through their partnerships, they have been able to support organizations throughout the country and reduce the potential for overlap or duplication of services.

TABLE 6.1
Items Carried and Distributed by the CPHA National AIDS Clearinghouse 1989-1996

	1989-90	1990-91	1991-92	1992-93	1993-94	1994-95	1995-96*	TOTAL
Requests	4,563	11,346	25,530	21,955	30,315	42,000	46,000	**181,709**
New titles carried	30	195	85	83	110	136	167	**806**
Total titles carried	30	225	310	393	503	639	806	**806**
Items distributed	925,346	2,309,939	3,000,000	1,922,816	1,304,000	1,450,000	1,300,000	**12,212,101**

Source: CPHA National AIDS Clearinghouse.

* These numbers reflect only the first three quarters of 1995-96.

Success

Key informants are of the belief that the Clearinghouse has had a positive impact on its clients. Perceived impacts noted by key informants include:

- the information and resources it has provided have been used to educate others about HIV/AIDS, have helped clients in making decisions about program interventions or policies, have empowered clients by providing them with the information they need to make decisions and have enabled clients to link to other resources and resource centres;
- the Clearinghouse has increased the capacity of local agencies to provide information to their clients;
- through its role with CANNET it has increased communication among HIV resource centres;
- it has increased the level of knowledge amongst the various target groups; and
- it has increased the capacity of Canadians and target groups to respond to the epidemic by providing the necessary information resources.

Cost-Effectiveness

Although cost-effectiveness data are limited, key informants described efforts undertaken by the management of the Clearinghouse to deliver its services more efficiently, including:

- ☐ clients are now being charged shipping costs for orders larger than one item and are being encouraged to coordinate their requests;
- ☐ on-going review of warehouse inventory is conducted; and
- ☐ the least expensive methods for shipping and for computer maintenance are being used.

Project Specific Issues

Charging clients for shipping of materials has resulted in a decline in demand for Clearinghouse resources. While one key informant felt that demand levels would increase again once clients became accustomed to the charges and their current supplies had dwindled, another key informant expressed some concern that some clients may have difficulty affording the costs. We note that data obtained from community-based groups in the course of the Lessons Learned Case Studies suggested that increased costs would indeed become a significant barrier.

(b) *Views on the Clearinghouse from Other Stakeholders*

Internal Review Results

According to key informants in the internal review, the Clearinghouse is viewed as an important resource by non-governmental organizations. Many of the respondents in the regions also mentioned utilizing this resource for themselves, as well as passing the information along to various non-governmental organizations. It is seen as an effective central distribution point for information to community-based organizations. Some of the regional Health Canada respondents provided the example of calling the Clearinghouse to determine whether a certain resource has been previously prepared with the intention of avoiding "reinventing the wheel".

The Clearinghouse is perhaps weak in its marketing of services and the definition of its core audience. The Clearinghouse is viewed as not having fully utilized its access to public health units across the country to convey new and emerging information around HIV/AIDS. It was noted that the Clearinghouse has limited utility for school-based projects and should be targeted to people working in the field. Other concerns with the Clearinghouse include the implementation of user fees (thereby becoming less accessible to non-governmental organizations). The efficiency of the delivery of Clearinghouse services and other AIDS programming offered by the CPHA was also questioned.

Provincial Survey and Inventory Results

Provincial/territorial respondents were asked to comment on the effectiveness of the National AIDS Clearinghouse. The majority of respondents agreed that the Clearinghouse has been effective and useful. These respondents described the

Clearinghouse as a good central source of information, providing access to a range of resources. These respondents also agreed that there is a continuing role for the Clearinghouse. According to NGO representatives, the Clearinghouse has helped them to find out what approaches have been used elsewhere with success, and has helped them to avoid "reinventing the wheel". Most respondents also felt that the Clearinghouse has helped them save time. While the information available through the Clearinghouse is generally available elsewhere, it is difficult to find and would require some searching. It was noted that easier accessibility through electronic searching may make the Clearinghouse's services redundant.

A few respondents expressed concern that users now have to pay for access to some materials. These respondents feared that cost recovery will limit access for small organizations with limited funds.

Stakeholder Survey Results

Awareness of the Clearinghouse among stakeholder organizations was high — more than three-quarters of respondents (77 per cent) were aware of the services. Awareness was somewhat higher among community organizations (82 per cent) compared to professional associations (64 per cent). It should be noted that because part of the sampling frame was obtained from lists of groups who have contacted the Clearinghouse, this awareness rate may be somewhat overestimated.

The majority of stakeholder organizations (87 per cent) reported that they had needed the services like those provided by the Clearinghouse. Of those groups who were aware of and had needed the services of the Clearinghouse, 83 per cent had used the Clearinghouse. Satisfaction with the accessibility of information through the Clearinghouse was high — three-quarters of respondents reported being satisfied with this aspect of the Clearinghouse.

(c) Conclusion

The CPHA National AIDS Clearinghouse is providing extensive, centralized access to information on HIV/AIDS. Opinions of the Clearinghouse are quite positive among provincial respondents and stakeholder groups, and increasing demand for information supports the continued need for this service. Some evidence indicated a need to review the Clearinghouse's marketing of services and the definition of its core audience.

6.3 AIDS Treatment Information Network

(a) Case Study Results

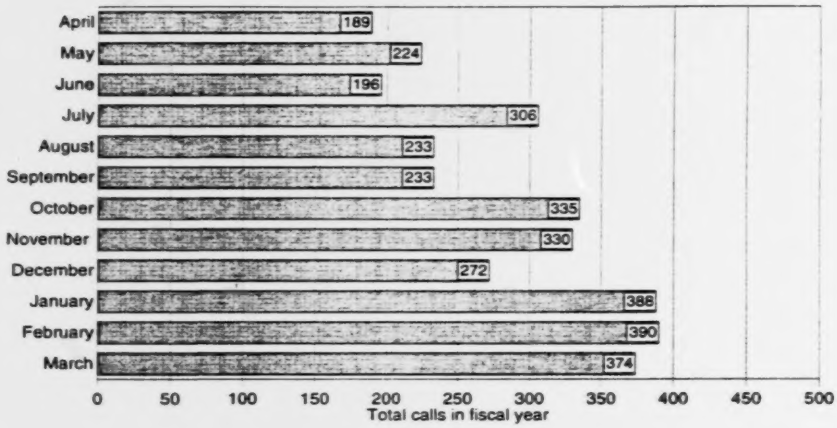
Continued Relevance

The AIDS Treatment Information Network is operated by the Community AIDS Treatment Information Exchange, a community-based group in Toronto. CATIE's Network is believed by its staff to be the only national, bilingual information Network providing a 1-800 telephone consultation service, print publications, Internet service and in-person presentations, workshops and skill building seminars. While potential for overlap with other organizations sometimes exists, the Network endeavours to build partnerships and to build onto the services being offered by the other organizations.

According to key informants, the Network is kept aware of the changing client needs through input from its National Advisory Council, requests for information made by callers, evaluations of Network services, conferences, anecdotes and the tracking system that has been implemented for the 1-800 service. Involvement of the staff and volunteers on other committees and in the community at large is also regarded as an important means of identifying needs.

The need for services provided by the Network was documented in a number of needs assessment studies. Key informants noted that because treatment information for HIV is extensive and developing quickly, there is a continued need for such a service. Demand for the services provided by the Network continues to increase, as evidenced by the increasing number of calls over the past year (see Exhibit 6.1), as well as the increasing number of documents being delivered by the Network's web site.

EXHIBIT 6.1
CATIE Network Calls
from April 1, 1996 to March 31, 1997



Source: CATIE

Success

Key informants within the Network perceived that it has had a positive impact on the people who have accessed its services. Perceived impacts noted by key informants, based on their anecdotal observations and some limited evaluative information, include:

- ❑ information provided has been used to educate others and has influenced treatment decisions and case management;
- ❑ links have been created with other resources through the web site and telephone referrals;
- ❑ although CATIE has influenced treatment policy and protocols through its participation on advisory committees, the information provided by the Network is just starting to be used to influence policy;
- ❑ information provided has increased the level of knowledge of the various target groups;
- ❑ information provided has increased the capacity of target groups and individuals to seek out and evaluate treatment information through the help provided on the telephone, through the skill building workshops and through the Network fact sheets; and
- ❑ the Network has improved the care and treatment for people living with HIV/AIDS and contributed to better health outcomes by providing them with needed information.

Cost-Effectiveness

Although data on cost-effectiveness are limited, the Network is considered by key informants to be efficiently operated. Evidence cited in support of this includes:

- ❑ the cost of administration is four percentage points below what is seen as the acceptable level for non-governmental organizations;
- ❑ overhead is regularly reviewed and last year was reduced by $190,000;

- in-kind contributions, donations, rebates and non-government grants have made it possible to reduce costs;
- the Network has made effective use of volunteers;
- potential alternatives for delivering services have been taken into account;
- AIDS organizations are asked to make copies of the Network's print publications for their clients; and
- delivery of services via the internet — saves in administration, processing, copying and mailing costs.

Project Specific Issues

According to key informants, it is important that a service such as the Network be seen to be credible by the people who access it. This includes providing unbiased information. Given the need for credibility, the importance of securing public funding for such a service was stressed by key informants, although a complementary role was acknowledged for private sector funding.

(b) Views of CATIE's Network from Other Stakeholders

Internal Review Results

The Network is perceived to be a useful source of treatment information, particularly in light of the rapid changes in drug therapies and other treatment regimens. Several respondents noted that the Network supports the notion of consumerism in health. The use of the Network may be somewhat uneven, however, and there may be some duplication with regional organizations. The Network is not operating at full capacity and requires better marketing of its services. Because it is a community-driven effort it has a high level of credibility among the HIV/AIDS community. It should be recognized, however, that the Network is a relatively new organization and it is difficult, at this time, to assess effectiveness.

Provincial Survey and Inventory Results

Not all respondents were familiar enough with CATIE's Network to respond. Those who did respond, about two thirds of those surveyed, agreed that it has been effective, and provided many of the same comments as for the Clearinghouse. Respondents noted that it provides easy access to information, and saves them time and money by offering one central access point. Respondents noted that the Network provides up-to-date information useful for a range of groups, including patients and the general public. The Network is also seen as providing early access to research results, as well as to information which is free of bias. While the information available from the Network is generally available elsewhere, it is harder to find and sometimes can only be obtained for a cost. These respondents agreed that there is a continuing future role for the Network.

Stakeholder Survey Results

Overall, 73 per cent of stakeholder organizations reported that they had a need for information about HIV or AIDS treatments. This was higher among community organizations (80 per cent) compared to professional associations (54 per cent).

Sixty-two per cent of stakeholder groups were aware of CATIE's Network and just under half (47 per cent) responded that they had needed services like those provided by the Network. Once again, awareness and expressed need for treatment information was higher among community organizations compared to professional associations.

Of those organizations surveyed, about one-half had used the Network to obtain treatment information. Among all respondents, thirty-eight per cent were satisfied with the accessibility of information through the Network. Over half (54 per cent) responded "don't know".

(c) Conclusion

The AIDS Treatment Information Network is providing a broadly accessible information service, as consistent with its mandate, mission and principles. Although in operation for less than the full length of NAS-II, the Network has become fully implemented and responsive to changing and increasing information needs in an efficient manner. However, the use of the Network may be somewhat uneven. The Network is not yet operating at full capacity and requires better marketing of its services.

CHAPTER

7

CORRECTIONAL SERVICE OF CANADA STUDY

7.1 Introduction

The Correctional Service of Canada's involvement in NAS-II arises out of the fact that inmates have been identified as a vulnerable population. Although precise data is not available, evidence suggests that the prevalence of HIV/AIDS in correctional institutions is much higher than in the general population. The only seroprevalence study conducted in a federal facility found the rate of HIV/AIDS to be ten times higher than in the general population. Although the transmission of HIV/AIDS is poorly understood in prisons, the high seroprevalence rates may be attributed, in part, to the large number of offenders who enter the system with long histories of substance abuse. A history of injection drug use is significantly associated with HIV seroprevalence among offenders. As self-reported by inmates in the Inmate Survey (1995) high risk behaviours such as injection drug use, sexual activity, tattooing and piercing also occur in prisons.

The Report of the Expert Committee on AIDS in Prisons, entitled *HIV/AIDS in Prisons: Final Report of the Expert Committee on AIDS in Prisons*, 1994 (ECAP Report) took a strong public health approach to the problem of HIV infection and prisons and a harm reduction approach to drug use. The ECAP Report identified fourteen major issues raised by HIV/AIDS and drug use in federal institutions and made a series of recommendations with respect to the health of inmates and staff, and the prevention of the transmission of HIV and other infectious diseases in federal correctional facilities. Under NAS-II, CSC committed to carrying out many of the ECAP recommendations. By doing so, the Service supports two of the three main goals of NAS-II: stopping the spread of HIV/AIDS and the development of appropriate and effective ways to provide care, treatment and support to people living with HIV/AIDS, their caregivers, families and friends.

The Correctional Service was allocated $400,000 annually under NAS-II. This was subsequently reduced for 1996/97 to $300,000. Although no person years were allocated, a portion of CSC's funds were used to staff the position of National HIV/AIDS Coordinator and a support position to administer the CSC program.

The mid-term review of NAS-II (1996) found systemic, organizational issues that impeded CSC's ability to effectively implement the initiatives of the National AIDS Program. More recently, in September 1996, CSC received the report — HIV/AIDS in Prisons: Final Report, 1996 (Jurgens Report). This Report assessed CSC's progress in responding to the ECAP Report's recommendations and identified new developments that had arisen since the release of the ECAP report. The Jurgens Report also assesses the federal and provincial correctional systems as being slow in implementing many of the ECAP recommendations.

7.2 Evaluation Design

This parallel evaluation study meets the requirement that a final evaluation report on the National AIDS Strategy — Phase II be submitted to Treasury Board by September 1997. The CSC parallel study addresses the three main Treasury Board evaluation questions:

- ☐ relevance and continued need;
- ☐ objectives achievement; and
- ☐ cost-effectiveness and alternatives.

The methodology for the CSC internal review included:

- a project file and document review;
- telephone interviews with Health Services staff in the regions responsible for implementing HIV/AIDS related activities and with Regional Coordinators Safety and Health;
- in-person interviews with National Headquarters Health Services management staff, the National HIV/AIDS Coordinator, and other National Headquarters staff with responsibility to implement aspects of CSC's National AIDS Program;
- a questionnaire to institutional Health Services Managers to assess the impacts of the initiative at the institutional level; and
- a review of the responses to the National Inmate Survey, conducted in 1995.

A summary of HIV/AIDS related policies and practices of international jurisdictions is available under separate cover.

A detailed version of the evaluation report is available as Research Report No. 2 of the NAS-II evaluation.

(a) Policy Development

In the area of policy development, CSC has revised two Commissioner's Directives to respond to ECAP recommendations; Commissioner's Directive 821-Management of Inmates with HIV, and Commissioner's Directive 803 — Consent to Health Care Assessment, Treatment and Release of Information. In addition, national guidelines for bleach distribution were prepared by a national working group to provide direction to operational units and to contribute to the consistent implementation of bleach distribution.

(b) Program Delivery and Evaluation

Under NAS-II funding support, program development activities have focused on:

- ☐ The introduction of harm reduction measures, specifically the distribution of bleach. Bleach was initially distributed on a pilot basis at Matsqui Institution, and based on the positive results of the pilot, CSC proceeded to national implementation.
- ☐ The development of health promotion, and HIV/AIDS education resources to assist health services staff in the delivery of HIV/AIDS education and training to inmates. A peer education program for inmates has been developed on a pilot basis at Dorchester Institution, and is currently being assessed as a model for national implementation (see Lessons Learned Case Study No. 7: Cons AIDS Network).
- ☐ Developing a better understanding of HIV/AIDS in prisons through general research initiatives. This has included incorporating into the Inmate Survey (1995) questions regarding high risk behaviours in its penitentiaries, a review of HIV/AIDS injection drug use and harm reduction practices internationally, and a review of legal and ethical issues by the Canadian HIV/AIDS Legal Network and Canadian AIDS Society (Jurgens Report).
- ☐ The inclusion of research designs in developmental initiatives such as the Matsqui bleach distribution and Dorchester peer education pilots.

(c) Issue Management

In the area of issue management, the Service has worked in partnership with external organizations and other levels of government to develop several of its initiatives under NAS-II. The most significant are:

- ☐ the Matsqui Bleach distribution pilot had input from both AIDS Vancouver and The British Columbia Centre for Excellence in HIV/AIDS;
- ☐ the Dorchester Peer Education pilot was developed with AIDS New Brunswick;

- the development of health promotion materials was a joint initiative between CSC and the province of British Columbia;
- recently a Federal/Provincial/Territorial working group to the Heads of Corrections has been established to address interjurisdictional policy issues; and
- CSC has contributed funding and other support to the Prisoners with HIV/AIDS Action Network for the first national HIV/AIDS in Prisons Workshop.

While there has been considerable external involvement in major developmental initiatives, there is considerably less involvement of community based AIDS organizations, or health and social service agencies at the operational level.

7.3 Assessment of CSC's Participation in NAS-II

(a) Relevance and Continued Need

As an operational agency, responsible for the delivery of health services to federal inmates, CSC's activities under NAS-II are consistent with NAS-II's overall objectives and with CSC's legislative mandate, its Mission and Health Services Standards.

The funding support provided by NAS-II enabled CSC to conduct several developmental activities to respond to HIV/AIDS. CSC has made some positive progress toward addressing the recommendations contained in the ECAP Report. However, more work remains to be done, particularly in the area of program delivery and research. A number of gaps have been identified with respect to the delivery of a comprehensive AIDS program in CSC.

The following represent the major work yet to be initiated or completed:

- ☐ While prevention education is provided to new recruits during their orientation, and to inmates upon reception, CSC needs to be more proactive in ensuring a consistent standard of delivery of refresher prevention education and training to both staff or inmates, and in providing its professional staff with the necessary education to enable them to effectively care, treat, and support HIV infected inmates. This was identified by the majority of staff as a major weakness of CSC's National AIDS Program. The needs of inmates will be addressed, in part, with national implementation of the Dorchester peer education model.
- ☐ Further assessment is required of the feasibility of introducing further harm reduction measures in federal institutions, including permitting tattoo and piercing services to be delivered by qualified inmates inside the penitentiaries, and methadone therapy, including maintenance.
- ☐ CSC has yet to complete work it initiated regarding issues respecting anonymous testing and related issues of protecting confidentiality in a correctional environment.
- ☐ To obtain a better understanding of HIV/AIDS in its institutions, CSC intends to conduct, in collaboration with Health Canada, a study of seroprevalence rates in federal institutions; and,
- ☐ The needs of women and Aboriginal offenders have yet to be assessed.

The scope of the work that remains to be completed will require CSC to undertake activities beyond the period of NAS-II. Funding through a renewed initiative or through internal reallocations would not only continue CSC's work in this area, but also extend support for established services and allow for the expansion of these services.

Staff expressed concern that many of these activities will not be sustainable in the absence of a federal role and funding support.

Within CSC there was general support for expanding the scope of the National AIDS Strategy to address all infectious diseases, particularly blood-borne pathogens. There was a concern expressed that the attention focused on HIV/AIDS had detracted from a focus of the issue of infectious diseases generally. Many of the education and prevention requirements are not unique to HIV/AIDS.

The view was also expressed that accountability for administration of the program should shift from Health Services to Correctional Programs. It was felt that this organizational shift would give HIV/AIDS a greater prominence and a greater likelihood of acceptance as a corporate priority.

(b) Implementation and Objectives Achievement

CSC's contribution to the achievement of the goals of NAS-II is contingent on implementing the ECAP recommendations and addressing the concerns raised in both the mid-term evaluation, as well as the more recent Jurgens Report. The most significant is the need to be proactive in developing a comprehensive program strategy, and an effective infrastructure and partnership approach to administer the initiative at all levels of the organization. CSC's response to HIV/AIDS has been characterized as being reactive.

Several additional issues emerged with respect to administration of CSC's National AIDS Program which significantly impacted on CSC's ability to achieve its objectives under NAS-II. They include:

- Inadequate analysis of the impact of the organization's receptivity to the ECAP recommendations, and the impacts and impediments to implementation at the operational level.
- Weak internal partnerships, particularly in involving all sectors and levels of the organization in strategic planning and defining priority areas of action. This may have contributed to weak "buy-in" from management and staff.
- Weak coordination, collaboration and information-sharing mechanisms to facilitate information-sharing between all levels of the organization, and particularly with the institutions. Operational staff reported that they did

not always have sufficient direction with respect to implementation of key initiatives. This contributed to inconsistent implementation nationally.

- Absence of clear accountability for administration of the program as a whole, particularly at the regional and operational levels, and for monitoring and reporting on progress on specific initiatives. Accountability was assigned on an initiative specific basis, such as in the bleach kit distribution, as opposed to implementing the AIDS program.

As a result of these weaknesses relating to the administration of the program, CSC's response to HIV/AIDS emerged as a series of stand-alone initiatives, as opposed to a comprehensive program response.

This evaluation has highlighted a number of areas requiring greater attention by CSC if it is to positively contribute to the achievement of NAS-II objectives. They include:

- Greater administrative and professional support to health services staff from their NHQ and RHQ counterparts.
- A stronger leadership role on the part of NHQ in establishing program standards to ensure national consistency in the implementation of various key initiatives (e.g. inmate and staff education, condom distribution).
- Related to the previous point, a strong role for NHQ in ensuring a nationally consistent standard for training of staff and inmates. This was identified as a major weakness in CSC's response to HIV/AIDS and one which, if not addressed, will adversely impact on CSC's ability to address the issues of HIV/AIDS.
- Providing levels of resourcing and support equivalent to that provided to pilot institutions when implementing initiatives nationally.
- Accountability at the regional and operational levels for implementation of the program.
- Improving information collection on HIV/AIDS cases, risk behaviours, and the care, treatment and support provided, to support management and evaluation of the program.
- Ensuring that evaluation frameworks are integral to developmental initiatives to enable the assessment of impacts of initiatives.

- ❑ A stronger compliance monitoring function by Health Services to ensure consistent implementation and corrective action when necessary.

CSC has just begun to make significant progress in addressing many of the issues raised in both the mid-term review and the Jurgens Reports. Most importantly, CSC is shifting from a "reactive" Health Services driven response to HIV/AIDS to one that has mobilized all sectors of CSC toward the development of an integrated, multi-disciplinary, multi-sectoral program initiative. Specifically,

- ❑ the development of an integrated, multi-disciplinary program framework, involving all Sectors of CSC, to address both ECAP/Jurgens recommendations and to establish a viable HIV/AIDS program;
- ❑ establishment of several committees, an Infectious Diseases Committee with regional members responsible for overseeing implementation of initiatives regionally, and to serve as a mechanism for coordination and collaboration on HIV/AIDS issues, an Implementation Committee, comprised of National and Regional staff to oversee the broad implementation of the National AIDS Program; a National Infectious Diseases Committee comprised of senior managers from the Service and from Health Canada, to advise Executive Committee on issues and actions required in response to infectious diseases;
- ❑ the identification of staff at the regional and operational levels with clearly defined accountability for implementing the National AIDS Program initiatives; and
- ❑ the identification of deficiencies in CSC's response to HIV/AIDS and plans of action to address them.

CSC has made positive progress toward developing plans of action to address the deficiencies identified in the mid-term evaluation and Jurgens reports and has made progress toward the goals of NAS-II. Institutional staff report that the initiative gave HIV/AIDS in prisons a higher profile, increased knowledge about HIV/AIDS in prisons, and increased CSC's attention and staff awareness to HIV/AIDS. Staff also reported that NAS-II had enhanced CSC's capability to deliver programs and services.

The most substantive progress under the initiative was in the development of training resources for inmates, such as health promotion training materials and inmate peer education and prevention measures such as bleach kit distribution. These initiatives were all funded through NAS-II to respond to the needs of inmates with HIV/AIDS. CSC actively promoted partnerships with external expertise and community-based AIDS service organizations in the development of these initiatives. CSC also made substantial changes to its policy in direct response to the ECAP recommendations.

Special funding under the initiative has provided opportunities for CSC to explore new concepts and develop program models such as inmate peer education, and bleach kit distribution. For the most part it contributed to the introduction of programs which responded to the needs of inmates which were not necessarily being addressed within existing resources.

(c) Cost-Effectiveness and Alternatives

NAS-II funding increased CSC's capacity to respond to HIV/AIDS by providing CSC the resources to focus explicitly on developing some of the more complex components of the ECAP recommendations. In the absence of funding support, these components would have competed for resources with other Service priorities and would have developed more slowly, if at all.

There was the perception that NAS-II funding could not be used in support of implementation, therefore, operational units were not provided NAS-II resources to support the implementation and delivery of the newly developed programs or services nor were health care budgets increased to reflect new responsibilities associated with implementation of the HIV/AIDS initiatives. However, inadequate person year resources was the most frequently cited impediment to effective implementation at the operational level.

LESSONS LEARNED CASE STUDY No. 7

CAN: The Cons AIDS Network Project, New Brunswick

CAN (Cons AIDS Network), originally recommended by the Expert Committee on AIDS in Prisons, was a pilot inmate peer education project in Dorchester Penitentiary, a medium security federal prison in New Brunswick. This project is a successful example of the partnership approach promoted by NAS-II, having been conducted as a partnership between AIDS New Brunswick, Correctional Services of Canada, and the AIDS Community Action Program as well as several other community-based and government organizations.

CAN's philosophy focused on empowering inmates to take control of their own health and well-being. Ten inmates, including two coordinators, received a 120-hour training program developed and implemented by AIDS New Brunswick enabling them to provide counselling, education and support to their fellow inmates regarding HIV/AIDS. Coordinators received an additional five weeks of coaching and training.

Once fully trained, the peer counsellors: distributed condoms and information (pamphlets, books, audiovisual materials as well as verbally); gave one-on-one prevention information and support; conducted interactive workshops; produced a monthly newsletter; attended a support group for prisoners with HIV/AIDS; corresponded with HIV-positive prisoners in other Atlantic Region institutions; and staffed an office at the penitentiary 36 hours per week.

Barriers overcome during the project included ignorance and prejudice of both staff and inmates; relaying the information in language that was easily understood by the mainly poorly-educated inmates; gaining inmate trust and overcoming fears of stigmatization.

A evaluation conducted by Brock University researchers showed that the peer education project: increased knowledge about HIV/AIDS; improved attitudes toward prisoners with HIV/AIDS; increased intentions to engage in risk reduction behaviours; and increased the incidence of HIV and Hepatitis testing. Those involved with the project regard it as a demonstration that peer counselling can be an effective form of prevention in prisons, and hope that the project can be extended and shared.

Should the National AIDS Strategy be renewed, CSC should be allocated resources directly, with control and direct accountability for expenditures. Operational units should be allocated the necessary resources, either through the National AIDS Strategy or through internal reallocation, to support implementation of new initiatives.

Expenditures associated with the developmental components of the program, however, are seen as extremely high, and CSC still has considerable work to do in this area (e.g. methadone maintenance, implementation of peer education). Continued NAS funding support is an effective way to ensure that CSC will be able to carry out future developmental activities.

Some staff perceived that the most effective means of addressing HIV/AIDS is to maintain a specific focus so that the efforts are sharply targeted and amenable to assessment in terms of their impact. Alternatively, others believe HIV/AIDS is one part of the broader problem of the transmission of blood-borne pathogens and believe that HIV/AIDS should be subsumed under a broader initiative relating to infectious diseases.

CSC is in the process of determining the cost requirements to continue with HIV/AIDS programming beyond 1997/98. Costs to implement the components of the program framework far exceed the resources that are forthcoming through NAS-II. Estimates for future funding will be incorporated into the National Capital, Accommodation and Operations Plan.

7.4 Summary and Conclusions

Considerable further work remains to be completed. CSC has recognized this and is in the process of defining where it should focus its resources in the upcoming years. The detailed evaluation report (NAS-II Evaluation, Research Report No. 2) contains 13 specific recommendations for this work. Resources will be required for further developmental work, particularly in the area of harm reduction, such as tattoo and piercing equipment in institutions, and methadone maintenance therapy. Work in these areas will likely be undertaken on a pilot basis. It is hoped that this developmental work will provide CSC with comprehensive models. More specifically, these pilots should provide CSC with materials and manuals describing the implementation of the program, and detailed reports on research findings and effectiveness of the programs. The initiatives can then be replicated in other sites.

Greater attention must be paid to the impediments to successful implementation of HIV/AIDS activities and initiatives at the local level, particularly the availability of resources, specifically person years to effectively administer the program in the institutions. The opportunities provided by NAS-II to undertake developmental activities at the National Headquarters level must translate into action at the operational level if CSC is to contribute to achievement of the Strategy's objectives.

CHAPTER

8 DISCUSSION AND CONCLUSIONS

Our presentation of the conclusions of this evaluation is organized as responses to the evaluation questions which have guided the overall study, with expansion to additional questions of significant interest for future national HIV/AIDS programming.

8.1 The Relevance of the National AIDS Strategy and Continued Need for Federal HIV/AIDS Programs and Activities

(a) Comprehensiveness and Appropriateness of NAS-II Elements

There is a wide consensus among all stakeholders and key informants questioned during the evaluation that the elements currently included in the National AIDS Strategy are both comprehensive and appropriate. No major elements were noted as missing from the Strategy, although weaknesses were noted with the implementation of some elements and some issues regarding division of responsibility between levels of government were raised. Moreover, there was no indication that the Strategy contains unnecessary or inappropriate elements. Given the extent of consensus on this issue, we can conclude that NAS-II's elements are adequately comprehensive and appropriate.

Some dissatisfaction with balance among elements of the Strategy, i.e., among research, care and prevention, was noted. Although Canada's proportional contribution to research is relatively great compared to that in other countries, there is a perceived need among many respondents, both inside and outside the research community, to increase research commitments. Some participants in the study also suggested that care and treatment will need to be a high priority in future if HIV infections continued to increase. However, other data suggest that the Strategy has been less successful in the area of prevention and at a minimum would need to be rethought in the next iteration of NAS.

(b) Complementarity, Duplication and Overlap

The activities supported by NAS-II are generally seen as complementary among themselves, with little duplication and relatively effective internal collaboration and communication.

Because activity of the federal government in HIV/AIDS-related health issues, particularly in the area of community-based activities, has the potential to duplicate the efforts of provinces and municipalities, the extent of overlap between jurisdictions was assessed throughout the evaluation. The qualitative results suggest that, at the level of program implementation, little duplication and overlap exist (although it should be noted that provincial key informants noted more overlap than did federal key informants.) In some provinces, this is because the federal NAS funding is the main source of HIV/AIDS programming, with the provincial government contributing very little. (The issue of relative provincial contributions will be discussed below.) In other provinces — notably British Columbia, Ontario and Quebec — provincial funding of HIV/AIDS activities exceeds the federal contribution. In some instances, highly successful collaborative mechanisms have been instituted to prevent duplication and improve collaboration, with provincial and federal representatives participating in each other's project review committees. This generally positive picture is corroborated by the stakeholder survey data, with three-quarters of respondents stating that they had not seen any overlap between provincial and federal activities. Overall, we can conclude NAS-II has succeeded in harmonizing its activities with those of the various other jurisdictions involved in HIV/AIDS.

An exception to this relatively positive picture are the coordination difficulties rising from jurisdictional issues in the funding of on-reserve and off-reserve Aboriginal Canadians.

While there is no significant duplication between federal and provincial/municipal activities, neither is there a great deal of jointly-shared, synergistic collective effort. The National AIDS Strategy can still best be described as a federal AIDS strategy, rather than a truly national and coordinated strategy, such as in Australia.

(c) Coordination, Monitoring and Collaboration

Mechanisms for coordination and collaboration received mixed reviews in the evaluation data. Deficiencies in NAS-II were noted in the mid-term review in terms of coordination and monitoring, and overall, our findings suggest that while it has improved since the mid-term review, there is still room for improvement.

At the time of the mid-term review, the coordination of the Strategy was the responsibility of the AIDS Secretariat. Coordination responsibility was subsequently moved to the HIV/AIDS Policy and Coordination Unit within the Health Promotion and Programs Branch. Despite these changes, stubborn weaknesses in coordination persist, particularly from the perspective of regional Health Canada staff and those outside the Health Promotion and Programs Branch. Particular issues noted were 1) while the AIDS

Coordinators Committee, a primary vehicle for enacting the coordination role of the HIV/AIDS Policy and Coordination Unit, meets regularly, its activities consist mainly of information sharing rather than strategic decision-making. This committee lacks the authority to respond effectively to strategic needs or issues and to fill the broad coordination role set out for it in the initial program documents; 2) the location of the Unit within Health Promotion and Programs Branch limits its strategy-wide perspective; 3) satisfying the needs of the bureaucracy for briefing notes and reporting materials dominate the efforts of the unit, at the expense of coordination and policy development.

Interdepartmental coordination was also identified as a weakness of the Strategy, with a need for HIV/AIDS to be integrated into policy development in a broader spectrum involving for example, Human Resource Development Canada, Revenue Canada, Indian and Northern Affairs, and Canada Mortgage and Housing Corporation. Given that the area of greatest need identified by respondents to the survey of people living with HIV/AIDS was financial support (although we must be cautious in generalizing responses from this survey to the entire population of people living with HIV/AIDS), these findings echo the original policy orientations of the Strategy, calling for a response which extends beyond medical and social service needs to embrace a more global and comprehensive model of support to people living with HIV/AIDS.

In addition, it was noted that NAS-II lacks a coherent and visible international strategy. This criticism of the Strategy was noted in the mid-term review and does not appear to have been corrected.

Finally, and not the least, a major weakness among NAS-II's coordinating mechanisms is the Federal/Provincial/Territorial Committee, which has been relatively inactive throughout NAS-II and has not played an effective role in supporting a coordinated national strategy. Similar federal-provincial mechanisms in Germany and Australia have been more effective, notably in Australia, where responsibilities of all levels of government are clearly defined within the national strategy.

These difficulties in coordination are somewhat apparent to other partners in the Strategy, but less strongly. Many provincial representatives felt that coordination and monitoring were effective, and many were simply unfamiliar with these mechanisms. However, some did feel that there was room for improvement. Stakeholders surveyed in community-based and professional groups rated the coordination of the overall Canadian response to HIV/AIDS as rather poor, with only 28 per cent stating that the Strategy is well-coordinated. Ratings of NAS-II coordination by stakeholder panellists showed marginally significant improvement between 1995 and 1997, although ratings of implementation adequacy showed significant improvement. These coordination issues do not seem to translate into problems at the level of regional or local service delivery, as a majority of respondents to the survey of people living with HIV/AIDS felt that services in their region were adequately organized.

(d) Enhancement of Partners' Capabilities

Evidence from several sources converges to suggest that NAS-II has helped the federal government's partners become more capable in developing, implementing and delivering programs and services. Key informants in provincial governments and umbrella AIDS organizations agreed that NAS-II has helped create an infrastructure of organizations and resources for HIV/AIDS within their provinces. When asked how much NAS-II has helped the partners deal with HIV/AIDS more effectively, most community-based groups and other stakeholders surveyed felt that NAS-II has helped provincial governments, national non-government organizations, health care workers, and community-based groups at least to some extent.

According to several information sources, NAS-II has been particularly successful in enhancing the capacities of community-based groups. Overall, stakeholders indicated that NAS-II's enhancement of its partners' capacities was greatest for community-based groups. Stakeholders also cite strengthened community capacity to deal with HIV/AIDS as an area in which the Strategy has been especially successful.

Community-based groups themselves state that their capacity to reach vulnerable or high risk groups, to deliver services, and to develop the skills of those delivering such services have substantially increased since 1993. However, only about half of this improvement is attributed directly to NAS-II. These groups report that their increased capacity has had the greatest effect on improving their efforts to reach men who have sex with men, with less effect in reaching youth and injection drug users, and markedly less on prison populations, Aboriginal people, and ethnocultural groups. Community-based groups also report that their capacity to plan and implement programs and participate in a network of HIV/AIDS resources have improved since 1993, but again less than half of this improvement is attributed directly to NAS-II.

Among all the stakeholder communities consulted, professional associations and the private (pharmaceutical) sector appear to have been least engaged by the Strategy.

Data provided by the Canadian Policy Research Network show that the relative share of federal and provincial/municipal contributions to HIV/AIDS prevention has evolved over the life of NAS-II. Provincial and municipal governments have increased their proportion from 69 per cent (42.1$M) in 1992/93 to 75 per cent (54.6$M) in 1996/97, demonstrating the capacity for enhanced development and delivery of services.

Evidence that the capabilities of the federal government's partners to develop, implement and deliver services and programs has been enhanced is also available from respondents to the survey of people living with HIV/AIDS. Again being cautious in generalizing responses from this survey to the entire population of people living with HIV/AIDS, these responses suggest that services and programs implemented by the federal government's partners are reaching a large proportion of people living with HIV/AIDS. Respondents report that they are receiving various forms of support in dealing with HIV/AIDS, with more than three-quarters receiving information and treatment support. About three-quarters also feel that at least some effort is being made in Canada to help those living with HIV/AIDS.

Overall, the evaluation findings support the conclusion that the capabilities of the federal government's partners to develop, implement and deliver services and programs have been enhanced by NAS-II. NAS-II has assisted in the creation of a national infrastructure of resources and services, from local community-level organizations to national information services, through which programs and services are being delivered and received by people living with HIV/AIDS. This enhancement has been strongest for community-based groups and less strong for provincial governments and health systems.

(e) Continued Relevance and Future Roles

There was an overwhelming consensus among all NAS-II partners on the continued need for a national AIDS strategy as well as federal involvement in HIV/AIDS programming, in a leadership as well as funding role. Supporting this perceived continued relevance is the recent movement of the epidemic into more fragmented and marginalized populations, notably Aboriginal peoples. It was the perception of most key informants, including most provincial government representatives, that the federal government must assume a leadership role which is unlikely to be taken on by the provinces in its absence. Recent developments in therapy and lower levels of morbidity and mortality have also raised a new series of issues about long-term care and treatment, income security, and social integration which are best dealt with at a national level in order to ensure equitable access for all affected Canadians. There is strong support for a continued federal role in research and regulatory matters. Moreover, the presence of a national strategy allows strong and progressive national leadership on an issue which continues to be tainted by stigmatization and discomfort and ensures national standards on some crucial issues.

The issue of continued federal support to community-based projects is clearly controversial. Among key informants at the federal level, there is a keen awareness that direct service delivery and community-based activities have traditionally been the responsibility of the provinces. Provincial governments are believed to be closer to their communities and thus better able to provide targeted programming. There is therefore some support for gradual withdrawal or reduction of federal support or for direct transfer to provinces. However, there is also strong defense of the federal role in community-based programming, for many of the same reasons given in support of a general federal role (for example, leadership on a politically unattractive issue, need for international coordination, federal responsibility for Aboriginal people).

A major issue in this debate over roles in support to community-based groups is the sustainability of these groups without federal funding. Key informants at all levels maintain that many community-based organizations would simply not survive without federal funding, particularly in provinces where provincial support is minimal. Panellists in the two-wave study agreed at both Waves 1 and 2 that there would be a negative impact on future activities if NAS-II products and services ceased to be available. The survey of community-based organizations provided a more detailed estimate: if federal funding were nearly or almost eliminated, these organizations state that they would be able to carry out on average, about one-half of their current activities.

The evaluation findings also show that there is uneven commitment to HIV/AIDS among provincial and territorial governments. The lack of provincial commitment to HIV/AIDS in some provinces is generally deplored. There is a strong feeling among all provinces that it is an important federal role to compel adequate provincial commitment. It was also suggested that the nature of the federal government's relationship with each province could vary according to mutually acceptable parameters.

Education and prevention activities were identified by both federal and provincial representatives as areas for greater sharing or joint responsibility. The progress of the epidemic to more marginalized groups and youth is seen as requiring targeted, community-based prevention activities, while Health Canada's expertise is seen to be in traditional national public awareness and education campaigns. While there may be a continued federal role in terms of education and prevention research and guideline development, closer connections to communities are believed to yield more targeted and innovative projects.

8.2 The Accomplishments of NAS-II and the Success of the Strategy and its Components in Achieving the Strategy's Goals

(a) Strategy Effectiveness

Effectiveness in Meeting Objectives

Overall, the National AIDS Strategy-Phase II has been moderately successful in achieving its objectives.

Stopping the spread of HIV. The qualitative, survey, and epidemiological data converge to the conclusion that the National AIDS Strategy has been partially successful in terms of its first objective. While NAS-II has likely contributed to reducing the spread of HIV among men who have sex with men, infections in other populations indicate that the Strategy has not achieved its prevention objective. It is currently believed that HIV transmission has increased during the period covered by NAS-II. However, the Strategy is perceived to have been responsible for marshalling resources (model development, surveillance, HIV testing) which enabled better targeting of prevention activities, for raising broad public awareness, and for maintaining a public policy focus on the disease.

Providing care, treatment and support. Key informants' perceptions of NAS-II's success in providing care, treatment and support to people living with HIV/AIDS suggest that the Strategy has contributed to the development and mobilization of an infrastructure of non-governmental organizations offering support to the HIV/AIDS community and that health professionals' skills in treating and caring for HIV/AIDS patients have improved. NAS-II is also said to have stimulated the development of HIV/AIDS policies at the provincial level. Professional associations responding to the stakeholder survey stated that improvements in information about healthy lifestyles and effective treatments had occurred because of NAS-II. About one-half of stakeholders surveyed believe that NAS-II has been effective in improving care, treatment and support (as compared to only one-quarter for stopping the spread of HIV). Recent declines in overall deaths from AIDS are attributed largely to improved treatments. Sharp declines in mortality rates for those on antiretroviral therapy in the Clinical Trials Network also indicate that the Strategy has created a synergy between research and treatment which has improved the outlook for people living with HIV/AIDS. Finally, the survey among people living with HIV/AIDS is most eloquent on this point: when asked what kind of help they are receiving in living with HIV/AIDS, the vast majority of respondents state that they are receiving information, treatment, and/or moral support. When asked to identify what kind of help they need more of, only 13 per cent indicated that they need more treatment.

An issue which requires attention is that of access among those infected with HIV to clinical trials and experimental treatments. Key informants in some provinces suggested that access was inequitable, with individuals in some provinces, notably British Columbia, having greater access, and those in rural or remote locations much more limited access. This finding is echoed in the survey of people living with HIV/AIDS: almost three-quarters of those responding indicated that they have wanted to be in a research study of new treatments, but only 40 per cent have been in such a study. Perceived access to trials among those who have ever wanted to participate is rated as relatively difficult.

Searching for effective vaccines, drugs and therapies. As noted above, mortality and morbidity rates among HIV/AIDS patients have decreased considerably during the life of the Strategy, largely because of new treatment regimens developed through research. While this is the product of an international research effort, the Canadian contribution is judged to have been significant, and the Canadian research capacity has been enhanced. The Strategy is also widely perceived to have been successful in expanding the knowledge base through comprehensive and reliable AIDS surveillance and epidemiological data, although work remains to be done in the area of HIV surveillance systems, especially for high risk groups.

Effectiveness in Reaching Target Groups

As indicated in the review of the epidemiological situation of HIV/AIDS in Canada during the period covered by NAS-II, we must be cautious in attributing the observed changes in the epidemic to activities sponsored or enabled by NAS-II, particularly since most trends were already underway before NAS-II was introduced. There are two major changes in the epidemic since 1993 currently being expressed in HIV and AIDS data: declines in the epidemic among men who have sex with men, and emergence of epidemics in injection drug users and Aboriginal people. Infections are also increasing among women. There is also increasing suggestion of a growing epidemic among younger men who have sex with men. Regarding the first trend, the evaluation findings suggest that NAS-II has helped facilitate the decline through effective education and services to this population delivered by NAS-II partners. Key informants throughout the country as well as community-based groups working directly with this population feel that NAS-II has been successful in reaching the homosexual community. Although there is a continuing need for programs and services for men who have sex with men, especially among younger men, NAS-II can be said to have contributed to the containment of the epidemic in this group. Moreover, this has been achieved through an inclusive, supportive approach which has contributed to the development of a network of partner organizations who state that they are now more able to effectively plan and implement programs and services because of NAS-II.

Regarding the increases in the incidence of new HIV infections among injection drug users, Aboriginal people and among women, NAS-II has been less effective. Although considerable efforts have already been undertaken, effective programs and services for injection drug users have been more difficult to implement, for several reasons: the nature of the population, initial resistance to needle exchange programs, political unattractiveness of this group, etc. Dealing more effectively with the epidemic among injection drug users will be a major challenge for future HIV/AIDS intervention. Many of these issues have been addressed in a recently-released National Action Plan on HIV, AIDS and Injection Drug Use.[19]

Major challenges remain to be faced as well in dealing with the increase in incidence in new HIV infections in the Aboriginal population. Although awareness and concern about HIV/AIDS have increased among Aboriginal communities, faced with the additional challenges of lack of national Aboriginal leadership and organization, the relative isolation of many Aboriginal communities, and the low priority of HIV/AIDS in the agendas of both national and community Aboriginal groups, NAS-II has not been successful in mobilizing an effective response nor in overcoming the structural impediments caused by the fragmentation of programs between on-reserve and off-reserve Aboriginal people. Key informants at all levels of government expressed great concern over this issue and stress its importance for HIV/AIDS intervention in the very immediate future. These concerns were mirrored by Aboriginal groups themselves: those responding to the stakeholder survey generally felt that the federal Strategy had no impact, or at best moderate impact on their issues or concerns. Almost three quarters felt that NAS-II had not helped their communities develop appropriate approaches to dealing with HIV/AIDS, and nearly 80 per cent felt that it was not doing a good job of reaching people in their communities. Aboriginal groups surveyed felt that NAS-II had had little or no effect on stopping the spread of HIV or providing services to community members

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19. Task Force on HIV, AIDS and Injection Drug Use (1997). National Action Plan.

living with HIV/AIDS. These challenges have been recognized in Medical Services Branch's recent consensus discussion for future HIV/AIDS programming.[20]

Regarding prison populations, progress is being made toward the development and implementation of a multi-disciplinary program framework to address issues raised in previous reports on HIV/AIDS in Canadian prisons and in the mid-term review. Over and above redressing the organizational issues that have impeded the effective implementation of NAS-II in the federal prison system, developmental work has been undertaken on the development of training resources for inmates including a model for inmate peer education, and the implementation of prevention measures such as bleach kit distribution. Support from the National AIDS Strategy is seen as an effective means of ensuring that dedicated resources to support the development of programming to meet needs in the prison population will be provided. However, as the prevalence of HIV infection is estimated to be significantly higher than that in the nonprison population and is strongly associated with injection drug use, considerable further work remains to be completed.

NAS-II Successes in Responding to the HIV/AIDS Epidemic

Over and above achieving its objectives to the extent that it has, the National AIDS Strategy's main successes are said by federal and provincial key informants to be: effective support to a network of community-based organizations and the network of research on treatment, with the resulting improved outlook for people with HIV/AIDS. As described above, data from other sources in the evaluation confirm that these are indeed strong points in the Strategy. The infrastructure created by NAS-II support to community-based organizations seems to have been instrumental in both developing community capacity to respond to the epidemic and intervening effectively among men who have sex with men. The improvements to date in mortality rates can

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20. Health Canada, Medical Services Branch, Focus Group Report, 1997.

also be regarded as a NAS-II success story, insofar as the research network supported by NAS-II has contributed to the development of effective treatments. Moreover, the strengthened HIV/AIDS research capacity will now be available in support of future developments.

The evaluation data suggest that the main areas where the Strategy has been less successful include response in the Aboriginal and injection drug using populations. Although community-based groups report some enhancement of their capacity to reach IDU's, overall the community-based infrastructure has not been able to respond as effectively in these populations, and the epidemiological situation supports this conclusion.

(b) Effectiveness of Research and Development Activities

The resources and timeframe available for the evaluation study did not permit a detailed evaluation of research impacts. However, several sources of information converge to suggest that NAS-II research activities have effectively contributed to NAS-II objectives. Key informants surveyed at both the federal and provincial level were in strong agreement that federal research and development activities have been effective and useful. Over half of stakeholders surveyed report that NAS-II research and development has had a great deal of impact on their programming. Almost all those who responded to the survey of people living with HIV/AIDS felt that research had been of at least some help to people living with HIV/AIDS.

However, perceived NAS-II research effectiveness varies by type of activity. According to the Canadian HIV/AIDS researchers responding to the stakeholder survey, the most effective aspects of research activity supported by NAS-II were contributions to the international scientific literature, a strengthened overall HIV/AIDS research capacity, development of new knowledge about effective drug treatments, improving epidemiological data on HIV/AIDS, and increasing knowledge about HIV pathogenesis.

Interestingly, about half of researchers surveyed believed that NAS-II research had not been effective in improving programs and services, in contrast to more positive responses by those who actually use the findings. Research on prevention is not perceived to have generated much new knowledge and, indeed, has received relatively less funding than research in either pathogenesis or treatment.

8.3 The Cost-Effectiveness of NAS-II and Possible Alternatives for the Federal Role

The resources available for this evaluation did not permit a detailed quantitative assessment of cost-effectiveness. Moreover, a study on the cost-effectiveness of NAS-II will be available in forthcoming publications from the HIV/AIDS economic research program coordinated by the Canadian Policy Research Network and funded by NAS-II. However, the data available to us suggest that NAS-II has been reasonably cost-effective. It seems likely that greater cost-effectiveness could be achieved by more effective targeting and balance among components.

Over the life of the Strategy, the federal proportion of total funds spent nationally on HIV/AIDS prevention has decreased from 30 per cent in 1992/93 to 25 per cent in 1996/97, while there has been an overall increase in expenditures. This suggests that NAS-II has been effective in increasing its cost-effectiveness through ever greater cost-sharing.

Data from the Clinical Trials Network suggest that the Canadian trials network is about 10 times as efficient as the American network in operating trials, taking patient enrolment and expenditures into account (but not accounting for differences between health care systems in the United States and Canada). In addition, the increasing proportion of prevention funds committed by provincial and municipal governments during NAS-II as well as the overall much larger provincial than federal contribution suggests that the federal Strategy's resources can be viewed as a funding complement to a more and more substantial provincial and municipal commitment. To the extent that NAS-II has stimulated the development of provincial programs — and the eyes of many key informants in both levels of government, it so did — it can be said to have leveraged its initial investment and ensured a more adequate overall response with without having to increase its financial commitment.

Informed perceptions gathered during the course of the evaluation suggest that NAS-II is perceived to have been very cost-effective by both provincial and federal key informants, in that prevention activities avoid the cost of new cases and treatment activities reduce costs of morbidity and mortality. There was a general consensus among federal key informants that the Strategy has been preventing enough cases per day to offset direct costs of treatment of infected persons. Provincial and territorial government representatives and representatives of provincial/territorial AIDS organizations generally felt that the Strategy has been cost-effective in preventing of new cases and expanding programming. Many respondents, particularly representatives of umbrella community-based groups, noted that funding of community-based organizations is very cost-effective, given the leverage provided by the volunteer base of these organizations. There was no strong feeling that NAS-II had wasted time or money by pursuing irrelevant or irresponsible activities, although the efficiency of some activities was questioned. Among stakeholders surveyed, opinions were divided about the cost-effectiveness of NAS-II, with roughly equal proportions stating that it has and has not been cost-effective.

Alternative sources of support to NAS-II components were difficult to identify. It was suggested that there be greater contributions from the private sector, greater insistence on funding responsibility from provinces currently not making significant contributions and greater contributions from provinces in cost-sharing, and better scrutiny of all research spending. Although community-based organizations and the national mega-projects have been asked to develop alternative sources of funding, progress toward this has been slow.

8.4 Conclusion

The evaluation of NAS-II aimed to include a broad range of perspectives on the Strategy, its implementation, and its effectiveness. Given the resources available, this inclusionary approach has sacrificed some depth for breadth, particularly in terms of quantitative linkages between program costs, outputs and impacts. However, the extent of convergence among the various data sources suggests that the main findings are robust.

The evaluation findings show overall that the National AIDS Strategy continues to be relevant and that there is strong support for a continued federal role. The Strategy has been moderately successful in achieving its objectives, with greater success in care, treatment and support and research than in prevention. Evolution in the epidemic indicates that there are new challenges to be faced in terms of prevention in marginalized groups, notably Aboriginal people and injection drug users. Finally, insofar as the data available allow us to draw conclusions, the National AIDS Strategy has been relatively cost-effective.

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